# Stella 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 3 July 2020. Stella was a Team Leader at a 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

For me the thing that always stands out when people come to us with an invisible disability, is the look in their eyes.  Like soldiers returning from war with the ‘1000 yard stare’ – often the invisible illness claimant will present with a similar stare, glistening, huge eyes pleading to be believed.  A combination of desperation and the same features that you see on the television where animals or hungry children in far off countries, beg you to rescue them with £2 a month.

They sit, usually with a great deal of discomfort in my room, trying to get comfortable on a chair, thinking that I too am judging them, that somehow what I am going to tell them will make them feel worse, that I too don’t believe them because they look well, or worse they look or act 'normal'.  And I reassure.  Sometimes it takes a whole hour just to get them to open up to me.  The interviews are all very similar.  I pour some water and push the tissues –  they always seem to take a tissue, which they ring into a long string, moistened with the sweat from their palms and then cry with relief when they realise that not only do I believe them, but I would do anything to help them.  Sometimes the tears are of anger and frustration.  Sometimes they are just tears of fear or despair.  It’s hard enough being ill, its doubly hard when your perception is that no one believes you.

There are hundreds of invisible illnesses but to me two types stand out. There is a physical one such as fibromyalgia – a truly horrific condition where you look perfectly normal but your inside is a different matter.  You hear the most awful things when you ask them where they meet the requirements and perhaps ask them to describe their pain.  ‘Like being shot’, ‘I can’t get comfortable’, ‘I get fibro fog and I forget’ and then they will pull out the assessors report.

The other people we often see (on DLA to PIP transitions) are those who have conditions that they were born with such as the autistic spectrum or those who have mental health issues, where there may not be physical issues at all, and because these people are so good at masking for a short while and most of these people have spent their whole life wanting to belong they agree with whatever the assessor says.  Assessors sometimes try to trick these people, by asking questions such as ‘You don’t need any help with’ or ‘I bet you can cook if you were allowed to’ for example.  This is particularly cruel.  Assessors also upset those with mental health issues by suggesting that the services they are accessing are not suitable or the medication they are taking should be more.

The problem you see with assessors is that they can be in my opinion pretty judgemental, yes I know its ironic that I am being judgemental with that comment.  But if I had a pound for every person who has told me that I don’t look ill therefore I can’t be ill – or that the assessors report was a clear fabrication based only on a judgement and that none of the evidence they took with them was taken into consideration.  I would be rich.

Indeed, when you get to do enough of these, you can almost predict what is going to be written in the assessment report because this document is clearly very much copy and paste in nature.  Assumptions will be made based on things such as eye contract, client looks nourished, etc yet when you attend enough of these medical assessments you realise that no one can make eye contact with someone who is continually tapping at a computer.  Serial sevens, give me three words to remember (even if you don’t) are all ways to judge cognitive issues – but its all so false.  The assessment process does not realise the personal cost of attending these assessments, how you will get up early, plan meticulously to the last detail how you will get there, worry about what you will wear and it is my own personal experience that men of any age with a female assessor lie.  My own husband has a heart condition – he doesn’t go blue, he does get breathless, he medicates himself well as without it he can’t get out of bed – this is a man who hasn’t made a meal in years – all of a sudden the things he could do at his assessment – I honestly thought he was going to disappear into a telephone box on the way home and change into ‘Superman’.  Thankfully, I had a good assessor who clearly saw through his bravery and bravado and gave him the right award that was agreed with point for point with the decision maker.  However, not everyone is lucky enough to have accessors that were in this case so honest.

My son with the same condition was not so lucky.  He had a paramedic who was absolutely determined to prove him a liar.  He has the same heart condition as my husband but his heart is actually, on echo (a test they do to determine how much damage his heart has and how well it pumps) worse than my husband.  He is small, slight, exceptionally polite.  I raised him well.  He does not question authority and despite letters of evidence from cardiologists treating him and his cardiac nurses, school nursing service, explaining the condition his heart is in – how he will tire when he walks, sleep most of the day if he exerts himself. He was originally on high rate DLA - but on transition to PIP at 17 only scored 2 points awarded as aids for reading - he has dyslexia and uses a violet coloured overlay and he was awarded more points by a decision maker for his walking that the paramedic who assessed him gave.

We went to appeal with him but I presented too much evidence on the day (I can do it for everyone else but my own family) – we were not heard.   A decision maker called a week later with an offer.  Anyway I am digressing – something I tend to do.

At appeal though I have never lost a case with an invisible illness.  I have probably done 100 or so cases now that have had to go to appeal.  See where the decision makers and the assessors often don’t tend to want to believe my clients,  I usually find that the judges and the doctors and particularly the lay persons at tribunal do have a far greater understanding and empathy with the appellant.  This usually leads to long awards often at enhanced rates.

Maybe they ask the right questions at the appeal tribunal, or have a better understanding of the law?  Or maybe they see so many people with these conditions that they soon get to know what impact these conditions can have on daily living activities or mobility having heard them so often and feel that they can award on that basis?   Who knows?  But at least when you come to my office for the first time I can reassure you that providing we go all the way to appeal you have a really good chance of coming away with an award that is truly reflective of your difficulties.

## Interview Transcript

I= Interviewer P= Participant

I So, I've just turned on the recording now and if you could just quickly confirm to me you've had the consent form and the information sheet?

P I have had your consent form and I have had all the information and I know that…I am aware of what I can do if I decide that I don’t want to go forward.

I Excellent, thank you. And you are voluntarily agreeing to participate in the study?

P I am voluntarily agreeing to participate in this study.

I Thank you very much. And so, to just get us sort of warmed up, how long have you been, you’re at [National Advice Organisation] aren't you?

P I am yes.

I How long have you been there?

P Eight years.

I oh so quite a long time.

P Yeah, yeah. I started as a receptionist, and then I moved onto Gateway which was a the initial advice, moved on to become a common adviser, and then I did all the tribunal work and they promoted me to Team Leader last year. And I still keep my hand in with the representation because I really enjoy it.

I That’s good, so you've got quite a broad view, I always find it's useful when someone has worked up in that way. So, it means you understand all of the different roles because you've actually done them.

P Yeah, I often joke with our CEO that the only role I've got left is his and he needs to be a bit careful. [laughs]

I [Laughs] So you still, you still do the representing as well at appeals.

P Yeah I do, I do still do it. I still keep my hand in because A. I really enjoy it and B. I’m pretty good at it, which sounds terribly big headed and I'm really not meaning to be. And I also do, I do the odd PIP form, but again, just to keep my hand in because it’s not a skill I'd want to lose.

I Yeah. And it's quite a lengthy process with all of those things, isn't it?

P Yes, yes it is, but um…and because things change so quickly as well. I think it's really important to keep your, you know, almost like your professional development up. So I do a lot of reading on Rightsnet, and yeah… that's what I was doing last night reading Rightsnet, my son thinks I’m very sad to accept my something very sad. I’m not ‘Netflix and Chilling’, I’m Rightsnetting at 11 o’clock at night [laughs]

I [Laughs] You know what, that's what I can call it now. So, your why do you say that you're good at it and why do you enjoy it?

P I’m good at it because of my success rate, I mean, if you look on anything like when the government decides, sorry, I know you’re going to have to transcribe this, all these ums and uhs are gonna really, really, really grate aren’t they?

I It’s really not a problem, it’s worse listening to my own voice back then any of your ums so don’t worry.

P No I’ve been here, and I’ve done this so… I'm sorry, can you repeat the question?

I So, what is it that you enjoy about it that makes you still want to keep doing them?

P Oh yeah, that’s it I was getting big-headed and telling you my success rate wasn’t I. my success rate is really high, and I mean, you look at the DWP official figures it’s about 70%, I think, of appeals that actually get withheld and actually go through and are allowed. My own success rate is, well it was 100% and I’ve done, probably, I've been telling everybody I've done 140-150 for donkey's years, so it must be much more than that. I’ve lost count. I’ve only lost one, and the one I lost was this lady with an invisible illness that was actually quite visible. And I knew that she'd already got the right thing for, you know, the right award. I knew she wasn't going to get the high rate mobility that she wanted, because the high rate mobility is only 20 metres and she could walk further than that, it’s further than 20 metres from where I'm sat at the moment to the car park and I know she could do it and I told her that she wasn't going to ,you know, there's no way she's going to get it. And she's like, ‘I just want my day in court’, her day in court was more important to me than the fact that I have a 100% success rate.

I That's interesting. What did what did she mean by wanting her day in court?

P She was so frustrated that she didn't think that she'd got the right award because she didn't understand that the law says, that if you can go between 0-20 metres that's high right now. Enhanced rate daily living is up to 20 metres whereas a DLA, which she previously had for the whole of her life, from when she was a young child almost, it was 50 metres. So she'd always had that high rate mobility, and she was so frustrated that she didn't get it. But she could walk more than 20 metres, and even though she couldn't walk, you know, less… she was still walking less than 50 metres, she was still walking more than 20. And it was so frustrating for her because she thought it was wrong. But when the laws changed and they changed the DLA when it's just 50 metres to PIP and it's 20 metres, and I mean, they, the government got away with letting them do this. Nobody was up in arms saying, well hang on a minute, that’s not the same. You know, nobody’s done that.

She's, she was one of those that was sort of 30-40 metres, and she wasn't going to get the high rate mobility she wanted, but she wanted to go to court and she wanted to tell the judge how unfair it was. And she got her day in court. Unfortunately, there was nobody there from the DWP on that day but she really enjoyed it, but on the day she was obviously having a really, really, really good day and we got to the situation whereby, actually, I was parking in the disabled bay and she was late and she was physically running into the court, of course, where we were late, they actually saw her run. So that, that was probably the first and last time she's ever run in her life. And we have actually had to stop on the way there and stop on the way back, because obviously [Local city] is about 30-40 miles, on a good day in a car. And we stopped at Sidmouth so that she could get out and just stretch her legs and have a little walk around, but she was still walking more than 20 metres in the carpark, because she went off for a cigarette so, we knew we weren't going to win but she wanted her day. And her having her day was more important to me than my reputation.

I How did she feel after the hearing?

P She was disappointed that she didn’t win but she did turn around and say ‘oh you were right’. Yeah, yeah, I was, wasn’t I?

I Was it sort of… still useful to her to have gone?

P I don’t think I could comment on that, but she got her say in court, which is what she wanted, she wanted to be heard and she was heard. And I mean, she didn't lose anything, I didn't think she was going to lose anything because often when you get people that come in and say, you have to sort of explain well you've got this award, and there is a chance that you could lose it. And I have heard of that happening for other people, it's never happened to anybody I've taken court, but I have heard that other people have been warned. ‘well hang on, you’ve said something we’re going to take your award away from you’. And I think that probably happens quite a lot in the invisible illness cases, because you look so well. And the same with my PIP forms as well, the only PIP form that I've done for about five years that I didn't get was my own son, because I didn't take my own advice and get somebody else to do it for him. I mean, we got it back, we did get it back, but that wasn’t the case it just came through and you've got two points. Well hang on a minute, you know, well done Mum, you tell me you’re really good at these. Mm I am normally!

I Well it's, it can be as much about who's reading it as who's writing it though, as well isn't it?

P Yeah…and I also think it is quite difficult for your case manager to actually sit there and understand that you've got a 16-year-old with, effectively heart disease. It's really complex, and it's just… because, again, because he doesn't look ill, he's got a really poorly heart, but it's the left-hand side of his heart that’s failing, not the right. So, you wouldn’t see, if you were looking at him, any difference. He doesn't go blue, he doesn't look ill, his SATS are ok, you know, they're good, they’re in the high 90s. And you wouldn't necessarily know that he's taking on water, unless he chose to show you, because he takes it on his abdomen rather than on his feet, so he's invisible. And on the day we took him to his medical, the paramedic that saw him had already made the judgement by the time he got into the room, that he wasn't going to get. And her smirks and her smiles when he was answering the questions. Her questions were very very, very, very, closed, so things like ‘you don't need’, and I've seen it first-hand and I looked at her and I said, you're not gonna give him this are you? And she said ‘oh well I can’t possibly comment’, but you’ll hear a couple of days before Christmas, which I thought was also quite mean, really. And I went, oh right, okay. After she sort of started saying to him, ‘you don't need’, ‘you don't need’, that then got to the stage whereby I looked at my 16-17 year old child, and I just literally just got hold of him by his hand and I said, just get up, we’re going. And I've never done that before either, so I don't know where that came from, and she looked, and I said, look, I said, I'm not exposing him to any of this. I said, I'll just get it back on appeal. And that's what we did it.

I Must have been quite tough for him to go through that as well?

P Well it was actually an eye-opener for him, because he’d always had DLA, and we’d always given him his DLA once he was a teenager. He'd always had certain, I mean, the DLA in our house has always been spent on extravagant things that him and his brother could share. So, it was kind of, he didn't want to understand at that time that he was disabled. So, when he got this letter through originally, he was quite pleased that he didn't get it. And I was able to…so he was quite pleased that he didn’t, you know, that he didn't get it because he was like, ‘oh, I'm alright’, you know. So I phoned up and was absolutely furious, I mean, as it was we didn't get zero points, we got two points in daily living for, believe it or not, reading because he used a violet overlay occasionally, and she had given him no points in the moving around that he had been previously being on low rate mobility, so the decision maker had given him four points there. So actually, he'd got more points for the decision maker, which is also unusual to what he actually got when he was assessed by the assessor.

I Yeah that is unusual for a decision maker to give more than what is recommended from the report.

P Absolutely. So that’s what the decision maker did. So, I phoned up and when I phoned up and asked for the medical report, the assessor's report to come through, which is something you can do, not many people know that you're capable of doing that before appeal but I did, because I know, you know, obviously working here. I saw what she'd written about him and it was just everything was a pack of lies, it was all copy and paste, all copy and paste what he could do and what he couldn't do. But the person I spoke to on the phone, even though I didn't say I wanted that as a mandatory reconsideration, took that as our mandatory reconsideration. So when we phoned up a little while later, when the first month came and he came to me and said ‘oh mum can I have...?’ And I was like, no you can't because I don't have the money love, you know, that was your DLA paying for that and all of a sudden, it kind of dawned on him that actually maybe his life was being enhanced by this little bit extra money, and he still wasn't able to do the things that he thought he'd be able to do, like, go and play rugby because at the time he was on warfarin and things like that, you know, it never happened. And all of a sudden, he was, oh I think I'd made a mistake here. And I said oh really? So we went to appeal, and being me of course, because I'm this super-duper person whenever anybody else is involved but I am lousy when it comes to my own family, we got there, and I presented to the judge 36 pieces of paper and was not at all surprised when he looked at me and said ‘oh come on Mrs [last name], you know we can't possibly read this’. Sorry! Um…I am sorry I’m rambling on aren’t I…

I No, no it’s fine, keep going.

P So you know, that actually happened, and they had until the 31st of October to make a decision and they phoned him on the morning of the 31st of October and said, would you like enhanced rate daily living, which he took. Cause he was on previously, on high rate care and low rate mobility but that's fine, you know, he got his four points because again the mobility is different on PIP to DLA, and he had enhanced rate mobility and we took that and, you know, I felt a little bit better then because I thought that maybe justice had been served.

I Was that the DWP that offered you that, or was that from the hearing?

P Yes, no the DWP offered it to us. They phoned him and said would you like it, and they gave it to him, I think, for up to five years or something.

I So they phoned up with that offer after your hearing but before the decision?

P No it was, the hearing was adjourned because they sent the paperwork, the 36 papers that I had finally got together… um of the various bits of evidence. I mean, I went to the school and I got things from the school, and I got things from the doctor and I got things from the school nurse, and I got another letter from our cardiologist, and another letter from the cardiac liaison nurse, that you know, that I put that all together with a really extensive diary and possibly my best work really, because that's what I did for everybody else, decided maybe I should do my son. And obviously when I gave it in on the morning, as you can when you go to tribunal, I knew they would probably sent us away but…you know, they did and then he didn't have to go through people asking him questions because the decision maker took one look at it and thought okay, maybe the assessor has got it wrong.

I So was that, that was all new evidence that wasn't submitted with the application originally?

P No I….it was, um… a little bit of both. Because the application I originally submitted his like last clinic letter and things. But the problem sometimes with paediatric doctors as well is they write clinic letters slightly different to adult ones. So, under the adult scheme, you end up with…um doctors will just write, sort of like two or three paragraphs of so and so, and so and so. And it's mainly just, you know. the facts. Like for example, pulse was 150 and blood pressure was 90 over 62 and we upped this and we upped that. Paediatric doctors don’t write like that, paediatric doctors usually start with: I saw so and so, in the clinic today with, you know, with his mother and his father [Name] was looking well. So, the decision maker sees, ‘[Name] was looking well’ and then they don't bother reading the rest of the notes, even though on that occasion him looking good is he’s not dead. When he originally got his DLA under special rules, because he was expected to die. His heart is really, really, poorly and his heart really hasn't improved, he's just somehow learned how to live with that heart. His heart function is really poor. And that was, that was what I’d submitted with all the original clinic letters, but because he was just gone over to adult clinic at that time, all the letters were still written in quite a baby way. So, and also, you've also got the thing that when you're doing the appeals, is it always has to be on the date the decision is made as well. So, if he deteriorated since that day I would have had to make a new application.

So that's another thing that you always have to be very wary of when you're taking people to appeal, is whether or not that's relevant to what you're actually sending in. So what I had to do was actually speak to his teachers, his head of year who sent in his school reports and said ‘yes we do notice he gets tired’ and ‘he does have a get out of school free card’, you know, so that he can spend an extra five minutes wandering between the lessons, and ‘we are aware that he's on diuretics and he can go to the toilet anytime he likes’, you know, that sort of thing. And I just found the care plan from the year before, it was just sheer laziness I think, which is what I said. I’m an idiot, I should have let somebody else do it, somebody else would have said, hang on a minute you haven’t got much evidence here, come on love, you know. But I don't think it would have mattered what evidence I’d sent in, the assessor had already decided that she was going to fail him before we even went in the room.

I Is that, sort of, is there a difference in the level of evidence that you have to give for say people with a more obvious disability and people with invisible disabilities?

P I would argue, in my situations, and what I’ve seen yes, yes, absolutely. Because if somebody walks into the room with one leg, you can actually see that can’t you? Or, if somebody has got an obvious disability, they’re stammering, you know, or they're sweating or they're breathless, yeah you can see that. Whereas if somebody is coming in with something, say for example, Asperger’s, or you know, particularly the higher functioning ones, the people that have learned to mask. Because you get that an awful lot, because these days people tend to get assessed quite early, and they can have 10 or 15 years of being in, for example, a mainstream school, being taught that they're going to sit still, being taught that you have to make eye contact, being taught that this is what society is expecting of you. And that actually makes it really difficult, because it doesn't matter that the second that they move out that room, I mean I've taken people to assessments before, because sometimes I do take people to medical assessments, I’ve taken them previously, for example to appeal, I will go with them.

And it's not until you walk down the road with these people that you really have a true understanding of what it is they see and what it is they fear. So, somebody, for example, with severe anxiety who you’re accompanying, you see how they react when, when a car goes past, or if something bangs on, you know, like for example, a motorbike backfires or something, and it pops, and then you actually see that person virtually climb into you because they're so scared by that noise. And I wouldn't even necessarily realise it's happened. And I can always remember, there was one time when we were stood outside the assessment place with a lady [who] had severe, absolute severe anxiety, she was very hyper vigilant. And we had to wait for a second while they let us in, because I don’t know if you’ve been to many of them, but you have to ring the bell and they let you in and then you have to go through security. Well, she was really concerned because one of the accessible points in [Local city] you go around the corner and above there's a gantry, a gangway, that goes into the place next door, and she was absolutely terrified it was going to fall on us. Absolutely. And it didn't matter how much I reassured her, in her head she'd already done the calculation and we were dead. People don't see that, because when she walked into that room, she took a cup of drink and I…I do think they look at you in the room, I know we all say that they do, but she took a drink, and she kind of stopped shaking once I’d grabbed hold of her hand, because I'm not terribly…I’m very not COVID safe but I'm… I'm quite a touchy-feely person when people are upset. And so, I would hold people's hands, I don't know whether I am supposed to do that or not, where the boundaries are. You know, I am 52 years old and I’m a mother, if somebody is shaking, I'm gonna hold their hand if they want me to. Um, yeah and I think she was very lucky that somebody realised just how bad she actually was. But 10 minutes later we were chatting to the bloke that was in there, and you could tell that there was something wrong with the bloke that was in there, because he had his sticks and, you know, and every two minutes he was moping his brow, he was obviously sweating and obviously in a great deal of discomfort and his wife was rubbing his back. But you wouldn't have told that there was anything wrong with her, she was nicely presented, she had her makeup on, you know, and you just wouldn't have told…once she'd calmed herself down and we'd got her into the corner, where she felt safe. So, she's at a massive disadvantage.

And it is also people that have got the, the health conditions, I always go back to Fibromyalgia, because Fibromyalgia is evil, it’s really nasty, horrible, horrible condition. But when people walk in here, if they haven’t got sticks with them and if you don't notice the signs on their face that they're in pain, because again they're masking, or they've taken handfuls of painkillers before they've even come in to see you, you wouldn't necessarily know there’s anything wrong with them because they look, and I hate the word normal but I'm going to use it, they look normal. You pass them in the street, and you would never think, and yet inside they’re complete wrecks, they've got fibro fog and everything, aches and…. when people described it to me, the first few times I used to do PIP forms for people with fibromyalgia, I would have to say I was going to just visit my supervisor, cause I'd go upstairs and cry, and then come back.

I Do you think that's something that you're, I don't know if you call them clients or service users?

P Yeah, they’re clients, we call them clients.

I Are they like aware of that as well when they're going to a hearing, sort of how they look?

P Some people are yes. Some say, ‘what should I wear?’ And I tell them to go comfortable. Because some people who get, particularly Fibromyalgia or mental health, and I've taken people to courts that have been treated particularly badly domestically, had horrible domestic violence and they get really bad PTSD. Because remember it’s not just PIP appeals that I do, I do ESA as well for people that can't work because they've got long-term health conditions, you know. And they can't go outside unless they’ve done their makeup or their hair looks nice, because they just feel so rotten that it's worse for their mental health, going out looking like, you know, less than polished. And although that's commented on, quite obviously in the assessment, I've never, ever lost anything where I’ve taken somebody that's looked immaculate because I will turn around and say this is what makes that person feel comfortable.

And they are very good, I find the tribunal judges particularly in this area, I can't comment from anywhere else, or maybe I’ve just got a good relationship with them, you know. I think, I think they are brilliant in this area and they're very good with people with invisible illnesses, they have a real understanding. So, they don't take any notice of the fact that a person has come very well dressed. I only ever had it once, when I had, I was actually accompanying an ex-marine and he looked really, really smart when I took him and the DWP (and she was training the DWP person at the time), um she was, she made a comment on how he looked and I turned around and I looked straight at the judge and actually straight at the lay person and I said well, he's a marine what do you expect? This is how he comes. And they said, and the DWP person said, ‘well, how can he be in terrible pain, he’s sat here for the last half hour?’. And I said, A. he’s taken something called a chemical cosh, I can’t remember the name of it but he decided to take that because he was really worried that he was going to get quite cross, and he didn't want to embarrass himself in front of me, believe it or not, because he was a lovely, lovely man. Uh and he previously had gone to prison, so it wasn't like he didn't know that he had a violent nature, cause he did. I said, I told him to behave, I've asked him to sit there and I said, he's a mine, he’s not feeling pain in the same way that you or I would do, he's gonna sit there because I’ve asked him to and he respects me. And he got everything he wanted, and the judge was absolutely lovely, and we did win that. Even though he came in a beautiful suit and looked absolutely gorgeous. He really made an effort.

Bless him though, actually, he was so pleased with the result that the next time I came into work, because quite often people will buy me a tin of biscuits or something, it’s not asked for, it’s not called for, it's not expected. He’d bought me a water feed for my chickens, so I was like ah, oh bless you. That's a bit awkward because I’m not supposed to accept gifts and was supposed to be able to share, so what I did was, we decided that I could take it home providing I made a few cakes with the eggs.

I That seems very fair, that's a way of getting round that.

P Yeah, we couldn’t share it otherwise unfortunately but yeah.

I What kind of questions do they are, sort of at the tribunal? Is it, is it different for invisible disabilities or is it just sort of a similar line of questioning?

P I think they’re all very similar, I mean I write what’s known as the submission and again I don’t know what your background is, I should really have asked you first of all whether or not you do many of these. But I usually write a submission, and then they will base their questions on what I've written on the submission. But often their questions are quite different, I think, and sometimes people look at you to say what on earth are they asking me that for? Because, they want you to give them the right result, just keep going, keep going, you’re doing really well, you know. So yeah, and I will, all my clients, they could be asking very strange questions, like what are they asking that for, but it's because they’re looking at the law and wanting to, you know… I mean, I always say that a tribunal is more like a job interview, really isn't it, where you have a slightly dodgy reference, but they still want to see you for the position. That's how I tell people anyway, because it makes it a little bit more human than, rather than oh gosh, I've got to go to a court and there's gonna to be a judge there.

I Do you think that, that perception of it being a tribunal and there being a judge has an impact?

P Yes. Yeah, absolutely, particularly if you've got people that have got criminal records for example or have gone to the family court for any reason. Yeah, I think it’s far more scary for them, the actual thought that you're going to a tribunal court, you know, and it's Her Majesty's Court Tribunals Service. And unfortunately as well, they've got two places in [Local city] where you can go, one of them is in a very salubrious office building, in the actual legal quarter as well, which is quite nice, you know, it's very, very nice. But the other place they sometimes go, if they think people have got a history of violence is the Magistrate's Court and if you're taking somebody to the Magistrate's Court who’s previously been there and been convicted, it's trying on anybody let alone...

It's quite intimidating when you go in and instead of having [Derek] who's the tribunal person in [Local city], who's absolutely lovely. He's actually also an ex-Marine, but you'd never think, he’s really nice. I have a habit as well, which you're going to enjoy transcribing this, of shoving what is important to me, other than my mobile phone, down my bra. So, I’ll get there and I’ll be fishing in my bra and he’ll look at me and say, ‘not again’ and I’ll say yeah! And he said, ‘you know I'm gonna do this to you, don’t you?’. And I said yes, and you know I’m gonna do this to you as well. And that’s like a little bit of banter that we both do to each other, which usually relaxes my people, my clients as well, because they've come to that conclusion that…well I’m not very normal am I, really? Let’s face it, I’m sure if you've done many of these interviews you might not have met another one like me. So, there I am fishing my change out of my bra and everything else that goes down there and, you know, and there he is with his wand going, ‘oh for god’s sake put them away girl’. Because I’ve got a little bit… like Fiona from Shrek but with Hattie James’ boobs, they come in about half an hour before I do, and this poor man. I'm 5ft3, and he’s probably about the same height as I am. Yeah, no it’s not good, particularly if I've got the underwire lacy one on and I've got, like exposed a little bit of, he’s like ‘oh for god’s sake’, or ‘oh god, is it you again Mrs [name]?’. I do get that a lot, even the clerks that are coming in, and are. ‘ah Mrs [name] how are you, and how is the family?’ They must think I spend an awful lot of time hanging around the courts or something but, yeah, it's different put it that way.

Whereas obviously at Magistrate’s Courts you've got two big burly sort of like policemen and there's no banter there. And you have to walk through the full, like the full thing, like you know, you literally have to take everything out of your bra and pop it in the tray and then it goes through. It's not as good as [Derek} standing there with his little wand telling me to turn around and bend over and wherever else he usually wants me to do, with way too much innuendo really. I like the fact that I can get him to blush… sorry it’s just you know. As I say, if I'm not holding people's hands under the table... I promise you I'm more professional than this [laughs].

I [laughs] I was gonna say, I wouldn't want to comment on how normal you are compared to my other interview participants but no one else has mentioned their bra, that’s all I’ll say.

P Well there you go! They don’t know what they’re missing do they.

I [Laughs] No. it can be the safest place to keep your valuables, so...

P It actually can, and I don’t like taking a bag in, because you can’t take it into the actual tribunal itself, so I tend to just take my keys and things. And, you know, maybe a little bit of change just in case I need and now obviously my phone and that's it, that's what I take in. And usually the bundle, that goes somewhere, but that’s usually under an arm. Looks a little bit less professional, I think with my Tesco carrier bag, oh no its Lidl today, I’m going up market.

I Are you back in the office now?

P No, no, we're not because we can't make our office currently Covid safe. But I am in my office today because I knew I was going to make a telephone call to you. So yeah, no unfortunately not.

I Are you still on the phone advice to people though?

P Yes, we’re doing telephone advice. Actually managing to do very well actually, filling in forms as well. We can do that all online now.

I Oh really, because that's, usually that's all paper based isn’t it?

P We found, somebody’s done one, in Citizen’s Advice or somewhere, but I've got a very good friend, who actually he was the one that told me that you were doing this and did I want to help, but I don't know if, you may well have interviewed him or not. But he’s from Bridport, and he, he is, he is absolutely brilliant, absolutely brilliant. So, he um, I can’t remember what I was going to tell you about him now…

I Think it was the forms?

P Oh that’s it, he found me one online. So, I’ve managed to put that to my people and we’ve actually got them online. So, what we can do, is anybody that signs up that wants a PIP form, we actually do the ones that we found online, and we print that out and send it out to people. So, we’re actually still managing to do PIP forms, but I see that there's not many people that are applying at the moment, it isn’t what it has been, it's really gone downhill.

I Yeah, it’s taken a big dip hasn't it?

P It has, which is a real pity, because the whole face-to-face assessment thing, as we’ve discussed before, is a bit of a nightmare but if you can get on the phone, then obviously you can have an interview over the phone, which is actually better than somebody prodding you, pushing you and making judgments about you because they can only base it on the phone. And I’ve found that the telephone tribunals seem to have been a lot, lot easier as well. See I thought they'd be harder, because I think that sometimes if you actually see the person you can see when they're in pain and you can see when they're struggling to walk. So, I actually thought that the telephone tribunals would be harder but, I've had probably, probably five or six telephone tribunals lately and passed them all, they’ve all gone through.

I How have you found the process of it being on the telephone?

P It’s harder, it is harder, because you never know when you're supposed to talk. So you sit there thinking, mm ok, and I’m not good with silences, as you can tell, you go silent, I’ll chat. So, that’s been…and also, again with… it’s harder for me because if I’m at home, I've got, obviously got the children, I've got children at home so it's not massively confidential. My mobile does not work very well from my house and every time you phone me on my landline, currently it's actually using my internet, they found what's wrong with it, but that’s…about 100 metres away under the [motorway], and they're going to have to dig it up to actually put my phone right, so I can't see that happening anytime soon. So, when it cuts out and it did, I just really feel for my clients, so I tend to come into work and just do it here.

I So, your clients do you, is it sort of like a conference call sort of thing, so they call in from home?

P Yeah, yeah, they call you all, and let you introduce yourself and it’s a little bit like what we’re doing here at the moment. The judge is there, and the lay person is still there and the, you know, they've got the bundle in front of them and you've got your bundle in front of you and then if I've written a submission, then the submission will be there. But it’s coming through so quickly at the moment, there have been a couple of times I haven't had a chance to write a submission, I've literally just sat in and listened and then just said a few things at the end.

I Hm, I was going to say are there more, because there was already a bit of a backlog wasn't there?

P They’re catching up, they’re giving people less… less time. Because… certainly here, we almost say we need the full 14 days. I mean, I have a paid member of staff now, but previously I'd work, I used to work as a support worker, so I needed that, that time to actually get the day off. Cause remember, the majority of our representatives are volunteers, and they have other lives, a lot volunteer elsewhere as well on different days, and some of us work, so if we need to get that time off to take some leave to go for a tribunal, which is what I was doing, then obviously we do need a bit of time to tell our bosses, that actually can I have next Wednesday off. They've been coming through really quickly like within days.

I Does that mean that some people are going without, sort of, a representative or a volunteer. Have a necessarily say that that's necessarily an issue.

P Yeah, I think they probably are, but then the tribunals were set up, so you didn’t have to have a representative, weren’t they? So, I wouldn’t necessarily say that that’s necessarily an issue.

I Yeah, it's um, it's an interesting one because I think just from the people, I've interviewed it's quite a mixture of organisations and charities and local councils that provide advice. And so, it can be, it can be completely different sort of where you are in the country as to as to what help you can get.

P Yes absolutely, and around here, I don't think we've got a lot of help, other than a [national advice organisation]. Our local council certainly wouldn’t go to appeals, or tribunals with you. Quite often when you talk to the other tribunal reps in rooms, it’s national charities that tend to come and help. Having said that, across [local area] itself, we've got quite a high percentage of, I think, as I said my, I was almost 100%, the person I work with here, he was almost 100% as well and the two specialists that we’ve got here, who are also attached to [South West area], they are both high 90s, do a hell of a lot of tribunals. So, we tend to…and to work from here, we've got quite high percentages of how well we can do. And I think across [local area] it is the same. I think we're all very high, but I don't think there's anybody else across [local area] that actually offers tribunal help other than us. Certainly not free anyway, there's a couple of people I think that do it paid, you know like Benefits and Work or whatever they're called, Fight back I think it’s called, Fightback from Justice. They get on the internet; they'll go to tribunals with you, but they do expect to be paid. And of course, we’re a free service.

I I’d imagine, not a lot of people contesting a PIP decision have money to pay for a representative to go with them.

P My understanding, I think they charge £90 for a PIP form or something like that, you need to… perhaps you might want to research that, how much it is because it might be interesting for your dissertation. My understanding is that they take a certain percentage of what you win, and remember, sometimes there’s a very, very, very nice backdate. If you've been waiting for a year and you get say enhanced rate, both, that’s what, 149-150 quid a week. So if you take 10 or 20% of that back pay, that’s a couple of thousand, especially if you work out, for example, if you took a child, child DLA got both, then you might end up with that percentage, you'd also end up with the Carer’s Allowance, probably end up with some of the £5000 pounds, if you take it over the year, that they would be picking up in extra disability benefits, tax credits for example. I know I once took a child to tribunal and when we worked it out, what the parents got, they were also benefit capped, I think it was about £17,000 they got. Well if I take 10% of that, what’s that £1,700 for an hour’s work? That’s not bad is it, we’re in the wrong job.

I No, well, I mean, it must be lucrative otherwise people wouldn't do it.

P No absolutely, absolutely.

I Yeah, it's a tough one, and as you say the process is sort of geared towards the judges and sort of the panel asking questions, so that you're able to go on your own.

P Yeah, absolutely. And I mean, really, what does a representative do when you get there?

I I don’t know, you tell me [laughs].

P Oh, have you never been?

I No, no.

P Oh no, ok, so when you get there, when you walk into the tribunal, obviously you’ve got the judge that’s directly in front of you and then to your left, or their right, there will usually be a doctor sitting there, for all the tribunals and then obviously with PIP, or DLA or AA you have the lay person that sits on the other side as well, so the Judge is in the middle. They usually actually, at the beginning of it, they will actually ask the representative if there is anything that you want to say and you actually, literally stand there and say, I stand by my submission, because you'd have written the submission which is basically just a letter which is saying, these are where you should have been awarded points and here’s the evidence that I’ve got for that. And by the time you’re finished doing that, you sit down and then the judge will, mainly asks, you know, the appellant, what's going on, explains what's going on. And then they will actually ask the lay person and the lay person, sorry they usually ask the doctor first, the doctor usually deals with things about mobility, usually. So, he'll ask questions, or she’ll ask questions about mobility, and then they go to the lay person and the lay person tends to ask questions about care. And then it goes back to the judge. And then at the end, the judge will say to the person if they’ve anybody else with them, like a partner or a friend, you know, is there anything you wish to add, and that person might say well yes, they didn't mention this, or that, the other. And then they say to the representative, if there's anything you need to add, and that would be the time whereby I might, in the case of an invisible illness, as I try to put that in my head for you, you did get something in there. They might say, is there anything you want to add and I might say, well hang on a minute, how much painkiller have you had today, particularly, if they’ve said that they struggle with their hands, for example, and where they're nervous, they’re waving their hands around, and I might notice that and say how much painkillers have you had today and they might go, well I’ve had some amitriptyline and this, that and the other. And I’m like, okay that's fine, you know, or I might just pick something up that I've seen in the papers, like for example, if a doctor hasn't given enough information, I'll say have you ever seen this GP? And they'll say no and, I’ll say well is that why they, they don't know you very well and they've just ticked nothing and sent it back and, you know, that's my role. Or anything I think they said that they need to maybe expand a little bit on, because I know the normal law.

Now I don’t know the law as well…well actually I probably do know the law as well as the judge, because of my Rightsnet surfing, you know, now I'm not doing anything more exciting. So, I've already got five children, and I've not got a TV licence, so you know, now we've got Netflix we don't need to chill, it’s fine [laughs]. So, I sort of like might have an idea in my head, where I want that person to actually say a little bit more, to make it easier for the judge to actually be able to give them the points. But apart from that, I think that they've been quite thorough. Quite often I just stand there and say thank you for your time, I stand by my submission and that's it. I don't do anything. I can't talk really on behalf, and I suppose the only other time I might be useful, is if the client has said anything that means that they, they might have put their award that they've got at the moment at risk, and in that case I would turn around and say, hang on a minute. Yeah, because they would talk to me as the representative then and say, you might want to have a word with your client to, you know, to withdraw, which you can do if you think that you've got an award and you've done something and they might take award away from you. It’s usually the rep that as you will say to… but if that representative isn't there, they actually tell the person there, are you sure, you know, you don't want to withdraw anyway. So, I’m really just a bit of confidence building and a taxi, you don't need me there.

I So what do you say, sort of largely your role is the application and sort of preparing people for the hearing?

P Yeah absolutely, I would say my role as a representative was preparing you for that day. So, making sure that you've got enough evidence that’s worth sending in, making sure you've got this submission written so that you don't have to sit there for three or four hours. Because if you're only looking for points, for example, you've got six points but they haven’t given you any points for preparing food, we accept the six points, so hang on a minute, perhaps we should have two points there, because I'm prompting so and so, get the, you know, get the evidence as to why you might need some prompting with preparing food, and that's it, that's what I would do. And then they will, I mean, they have the option to look elsewhere and sometimes they do and they think that they've, if I’ve missed anything or somebody else hasn’t missed anything. They might ask a few questions, but generally they're pretty good at just looking and just asking questions where I’ve written in the submission. And that is my role and it's my role to be there the night before, when it's half past six and you’re scared, sort of for them to text me, can we just go over what’s going to happen tomorrow. I don't think that, if I've done my job well enough, at this stage with getting the evidence, asking doctors, you know, looking at places where you might be able to find some evidence… and the thing with invisible illnesses as well, is that, it's more difficult for you, if you haven't got evidence.

I’m just going to have a sip of water. So again, I'm gonna go back to fibromyalgia, if I may. It really helps if you’ve gone to see a rheumatologist, so you've got the diagnosis, because even though they say for disability benefits, it's to do with how much you care, or to do how it's affected, it actually really helps to still have a diagnosis, particularly if you have got an invisible illness, in my opinion.

I Have you found that in most of your cases?

P Yeah in all of them, in all of them. It's really important that if you've got that invisible illness, that we've got some medical evidence somewhere that backs that up.

I Why do you think it makes such a difference?

P Because I think that, you don’t look ill, if I’m honest. So, you need a doctor to say that you’re that ill. Or else, I suppose, it might, because… when you work where I work, and you hear people, a number of people that come in and say oh so and so from down the road, he's got a car, and he's got this, and he's got that, and he’s got the other and he's got nothing wrong with him. Really? You sure he hasn't got Fibromyalgia or autism or Asperger's or mental health issues, because remember you only see him for five minutes when he might be walking to his car, maybe with his kids. You don’t see him the rest of the week when he's at home, you know, in a corner, because we don't know what goes on behind our closed doors. And these days, yes, I know you'll probably… people probably argue that there's some form of benefit fraud goes on, but it is incredibly difficult to pull the wool over the eyes of anybody that's trying to get disability benefits and I would argue that until, you know, the cows come home. There is so little fraud, because you have to have evidence. So you're gonna have to have persuaded a doctor that there's something seriously wrong with you, and a consultant, and I think the chances of persuading a GP and a consultant, and possibly a nurse that there's something going on, are a very, very slim. So that gentleman that’s got the car down the road has either been on DLA for donkey's years and hasn't been looked at for PIP yet, in which case he will lose his car if it is not genuine. Or, he's genuinely got something really seriously wrong with him and you just haven't chosen to see it.

I Have you had many cases with invisible disabilities where people haven't had that medical evidence?

P No. I don’t think I have really because I would always ask them to get it.

I Hm, is it do you think, so by the time people have got to the point of being willing to go through the process to get PIP or ESA, um that's already been quite a long process through doctors and stuff, as it is?

P Sometimes. It depends what you’re talking about, because obviously if you’ve got a child that’s got Asperger’s that going to really struggle to make it in society, for example, because they just don't understand people and that leaves them incredibly vulnerable, then that probably wouldn't take too long, because the parents would be aware that they've got, that their child’s got this and they already have DLA and significant evidence that’s been built up from years and years and years of school because the vast majority of these people would be diagnosed earlier these days. So, they would be making the, you know, going through the PIP process at 16-17, there's still a lot of evidence out there for you. But for somebody that's inherited a condition, you know, all of a sudden they’ve had a heart attack or something like that, then, that's also quite, quite invisible, that the, you know, the paperwork would be there but it might take a little bit longer.

But I think that, usually by the time they come here to get PIP, they've been ill a little while maybe, because this is like a final straw, this is like accepting that it's not gonna get any better. And they're the ones whom I talked about in my email, you know, you can tell that they come in here and they've got this like look. The please believe me look, you know, the same look as you get on the television when somebody is trying to persuade you to give two pounds to.... I think, sort of like African children that are starving, you know, that real pleading look, please believe me. Because I think sometimes, GPs might believe them and their consultants might believe them and their families certainly believe them, they are very aware that they are, you know, the man or the woman down the corner that have got a car and there’s ‘nothing wrong with them’.

I How do you think that lack of belief, or perceived lack of belief, affects what advice…and what your role is to help them through to the tribunal?

P Um… I think there comes a time when they just get fed up and quite angry that they're not believed and that's usually at the time that they've chosen to go to tribunal. Because you choose to go to try to go to tribunal, you don’t have to go to tribunal, you can just accept the fact that somebody said you're okay and not do anything, and that is an option. So, by the time people are coming to tribunal, I think they’re quite angry, I think they’re quite frustrated, I think they want to have their day in court. They want to say, hang on a minute, something’s not quite right, you know. And also, its financially as well, you've had to give up work and if you get PIP and if you get, ESA for example, and get put into the support group, that’s about…about every week what you’d be earning probably if you were working full time on national minimum wage. It’s not a huge amount of money we're talking about here, but it is a life changing amount if you can't work anymore. So, it’s almost like they have to go, because you either go or you starve. I mean, we are at that stage, if you get put in the work-related activity group, on ESA for example, that's £74.10p a week that you're expected to survive on, it's not a lot of money. You know, you have to get the PIP as well, alongside it. I mean, we're not talking huge amounts of money here, but we are talking, huge amounts of money for people that need it. Because if you get PIP, that is the difference sometimes between you putting the heating on and you eating. And I know that sounds terribly dramatic, but it's what I feel.

I No, no it’s right.

P And often if you’ve got these illnesses, and your partner has to give up work to look after you, Carer’s Allowance is £67, it’s not even the £74… not a hell of a lot of money is it, to give up work. And again, I know that through my own experience with my eldest son, um… couple of years later we went and gave birth to another child who we were told would be nowhere near as bad as his brother, and they clearly didn't have a clue, because he was and worse. So, we ended up both myself and my husband having to give up work and we went from really good salaries, amazing salaries really looking back at it, if you take this was 20 odd years ago. Um, [laughs] so, I think Income Support at that time was about £50 a week. And I'm rather really ashamed to say, when they first told me to apply for DLA for [Desmond], which was worth about £55 I think they thought I would get at the time, I can’t remember, it was a while back now… But I was like, no I can’t be bothered to fill in the forms, because I could earn that in an hour and a half, and I didn't want to take the money. And I'm really ashamed of that, that I could be that… well it’s not snobbish, it’s just oh you know, no, because I was on really good money and my husband was on really good money and the benefits system was… it’s broken, it doesn't pay enough. And actually, coming from that amount of money onto, trying to survive on Income Support, was really challenging and it could happen to anybody because it happened to me.

And that's what people don't get, is the fact that you're wandering around at the moment, but nobody knows whether or not tomorrow you're going to come down with Fibromyalgia or Lupus, or other autoimmune diseases that happen in your 30s/40s/50s. So, and it does, everyday this happens to somebody else and all of a sudden you could be sat there in your high castle, you know, judging everybody for what they're not doing and these terrible taxpayers that aren’t paying the taxes because they’re on benefits and then 10 minutes, 20 minutes later, all it takes is a car crash, you know, it’s all it takes. And that's it, your life is over and you're in here, sitting in my chair, with my tissues, with me telling you it's gonna be okay and I'm gonna really help you and you are crying your eyes out because your life has changed overnight. And nobody can see that you look any different, because you can't tell that your spine’s broken, or your legs don't work the way they used to, or you've got ‘fibro fog’. But I'll believe you and I’ll look after you and I’ll take care of you, because I know it happened to me, and it could happen to you.

I It’s interesting what you'd said about um, I guess you’d describe it as like the stigma of accessing the welfare state...

P Oh absolutely, it’s a massive stigma still, even today. Even today after millions of people have had to go on Universal Credit because of COVID-19, there is still a stigma. You know, people are ‘really sorry I have to claim benefits’. No, no you’re not really sorry, that’s what it’s there for, you’ve worked 40 years of your life, you’ve paid into National Insurance, you’ve paid your taxes and the stupid thing about oh everybody has to be a taxpayer- we're all taxpayers. VAT is still a tax, it all goes into one pot it’s not like…oh hang on a minute sorry, I'll digress…this is not useful for you is it? You know, that's fine.

I No, it's all, it's all related. It definitely is, because I think it makes it… there are several different things that make it hard to decide whether to apply for benefits or not, um...

P Yeah, I mean the whole, the whole system, it makes it harder as well. You know, the fact that there isn’t a PIP form online is ridiculous. There’s an ESA form, but you have to be told that you can fill it in. And there’s an Attendance Allowance form that you can fill in, you know, today if you wanted to claim for Mum, and even the child DLA form’s there but not PIP. Why? I don’t understand. Do we not want to accept the fact that adults get disabled too? Probably not, it’s a bit scary isn’t it? It’s like this Covid thing at the moment, isn't it, you know, you've got a horrible virus out there that's actually just taking healthy people and not so healthy people and you never know how you're gonna get it or what's gonna happen. And we're all terrified. So perhaps we’re just terrified of the thought that it could happen to us and that’s why there’s no PIP form online. Who knows? Or is it that they want to make you really work for it, that you have to phone a very scary call centre, give everybody your most personal of details to some bored-sounding person and if you do it often enough, bless them they do sound terribly bored, because I think they've got, they must have a, we've got to get this done in 20 minutes. So, you end up with them being quite relaxed and towards the end its blah blah blah blah blah. And actually, if you're scared or you're nervous and you're really scared, somebody's talking all this information to you, it's mind blowing.

I Definitely. Have you found so, like, particularly with the personal nature of this, the information you've got to give, is that something that is quite difficult to manage with your clients?

P Well of course it is, of course it is. Especially with some of the questions that they ask. A person, you know, a stranger comes in, and they are strangers, they brought in their PIP form and never seen them before, and by about question four or five I'm asking them, are you incontinent? Can you wipe your bottom? Can you, you know, how often do you wet yourself? It’s not the sort of questions you… you know, doesn't matter how friendly I am or how lovely I try and be and I do. I mean, I make cups of tea and, you know, and we make it almost like a day trip. I mean, I've once filled in a PIP form for a particularly poorly client who couldn't sit at all, she actually laid on the floor, and I made a snug bed for her out of all my, I call them my dog basket jumpers upstairs, because I've got a set of jumpers here because it gets quite cold in the office and I don't like putting on the heating because it dries it out and then everybody's coughing and that was before COVID, now oh my god [laughs]. I had her in the corner, because it was the only place that I could put her to keep her comfortable. And I turned down the lights, I switched off the light and put on a little side light and actually it looked more like a front room in here really, and she did actually fall asleep and I just left her for the rest of the day, shut the door. She woke up a couple of hours later and I made her a cup of tea. So that's how I run my office. And thankfully I've just got, my CEO just walks in and just, you know, shrugs his…everything alright? Yeah, fine here have a biscuit, he’ll go upstairs and just let me get on with it. But, you know, yeah, it's hard… to say well you’re gonna have to do this telephone call, yeah, it’s not good, not good at all.

I How is it different, so in the tribunal you're not able to control things like snuggly cushions and making them feel more comfortable?

P Well actually what we can do, again, I don't know whether I can shout for the rest of this area but certainly in this area, [Local city], they are amazing. The judges, the circuit judges, um for example, when you walk into the tribunals, the back of our tribunal, I don’t know if is the same everywhere, there's a whole selection of chairs. I don't know when I got them from, I think half of them have been stolen from Wetherspoons between you and me, you know, we’ll keep it quiet. And I love that, because I can actually look and say, which chair, would you prefer? And our judge always says, the judges, there's about six or seven of them, they always say, please don't sit there if you're uncomfortable, get up and move around. And I've even actually once had the judge, who clearly, probably didn't like the DWP person, but was probably a little bit more professional than that, actually asked the person from DWP to switch off the overhead lights, because she thought it was glaring for our client, and shut the doors, you know, so it was nice and cosy for her. So it's not like they don't make the effort because, I don't know, I can't say for other courts but certainly in [Local city], there was always a selection of seats, there’s always tissues, there’s always water, you know, and I can pour water for people, and they always, always say, take a break whenever you want to take a break and if anybody gets upset, I’ve never once known them, not to say would, you like to take a break for a few minutes. So actually they do their absolute utmost to make you as comfortable as you possibly can be, you know, within the constraints of what they can do.

I That's really good, because I think something that's come up in quite a few of the conversations I've had is, so the idea of accommodations, it's very difficult to know what to do for people with invisible disabilities. And I think a lot of the accessibility is, you know, ramps and hearing loops and that sort of thing.

P Well obviously there’s not ramps at…at because its flat and then there’s a nice lift, but it’s a nice lift that’s quite a posh lift, and it’s not far to walk and there’s loads of spaces and [Local city] is particularly, almost salubrious really. It does feel like you're going into a corporate environment rather than a judgey one, and even so far as if you've got somebody that won’t go into a waiting room because there’s strangers there, they actually let you sit in the corridor, and there’s seats in the corridor. You know, they are very, very accommodating.

I That sounds really good. I think it's um…it varies quite a bit doesn't it.

P I’m sure it does. I mean, I can only talk about, as a I say, I can only talk about [Local city] and I always get the feeling with [Local city] as well that they, they want to give your client an award, you know, I just do. I don’t know why I do; I just do. They’re very fair, the judges are very, very fair.

I Well and it sounds like you've got to know quite a lot of the people that you will be… like on the panel or who work in there.

P Yeah, I think we've got, because again I suppose it must be in the West Country, there's only a certain few, there’s not many. Um and I have got my favourites [laughs]. And sometimes when I think oh, it's that judge on, yes, no we're gonna alright, she’s really nice, don’t worry, she’s great, you know. Um, and that’s not to say that, I don’t suppose for one minute she’s a pushover, because I have heard her with other people as we've gone past, but she's always been, there’s one particular judge, that has always been very kind to me. Um and the doctors, yeah, and there's an absolutely amazing, um, one of the lay people as well, who's quite disabled herself, she goes around in a little mobility scooter and she sits on there. And she's the one that, when this DWP person was laying into my marine, I could, I happened to catch her eye, I'm very unprofessional, and she looked at me and she gave me a little wry smile and I gave her a massive smile back, and it was almost as if she was going, yeah, you know, [laughs], yeah , yeah just keep quiet for a couple of minutes, you're gonna get your pay, and I’m like grrr. There must have been a bit of steam out of my head, or something, but she definitely gave me…and even the judge on that occasion, she looked at me and said just calm down, you know, I don’t want to have to stop you, just calm down, you’ll get your point. Because she did actually turn to me and say, ‘what do you think about that then Mrs [name], I can see you want to talk?’ Yes, yes I can judge, you know! And I just thought that was quite lovely really, but then again, I might be reading something into body language, I've been watching way too much *Lie to* *Me* on Netflix, that might just be her normal stare, and I was like, oh that's quite a nice smile, you know. I do get the feeling that particularly this area, they're not out to be cruel, they’re really not.

I Have you found that dynamic between the panel members as well?

P Yes, there is a great dynamic between them, there is. And it's nice though, because it feels like they're all working from the same song sheet. Particularly the doctors, there’s some really, really nice doctors that work on these panels, absolutely lovely doctors, I can't fault them. They seem to really know their business, and around invisible illnesses as well, you know, if somebody has got a mental health condition or something like that, they will turn around and say, I think one of them might be a psychiatrist actually. He's really good, and he’ll say, now I understand how stressful this is for you, and you're doing very well, and if there's anything you want me to do just put your hand up and it will be fine, you know. Yeah, I don't know, maybe we're just lucky in [Local city]. I know we're lucky in [Local city] because when our CEO took over he was like, oh you’re going to tribunal panel… and myself and the people that work here were like, yeah, no it's okay, it's fine, they're fine, they're really good. Really? Actually, the media doesn't want you to see that they’re human does it, they want to sort of demonise these people to stop people from going, course you do. And then when you get there and you realise actually, they're human and you probably passed them in Sainsbury’s the other day or, you know, you may well have seen him in [Local city]. Well obviously… that’s not the case, because if that happened and it has happened a couple of times, that people have known people, or that doctors have known people. One of our local GPs actually is a tribunal rep and there's been times that he's been on the board and we've had to come home, because obviously it’s a conflict of interest. But yeah, no, the dynamic is interesting, it’s interesting to see how they all work. But again, I think we've probably got quite small circuits, they all know each other.

But it is, it’s mainly kind, it just feels kind. It’s almost like a positive atmosphere when you go in there.

I It must be quite different from their, sort of, experience of the assessment.

P Yes, yeah, I can’t say the same is true for quite a few of our assessors round here. There's one or two of them who you just know, you know, you see their name and just think argh… really. Although having said that, one of the really, really, awkward assessors that always turns everybody down, my husband got for his PIP and she turned around and said to him, oh you know, to try not to worry, you know. And I thought, well that was really nice of you, because I recognise your name… you know when you recognise someone’s name and you think, oh god no, what am I doing here? But my son's experience, again, was totally different and he got an assessor that I knew from her name, that, you know, quite, quite often, we can see that she turns people down. But then I don’t see the one she passes, do I? that’s the thing, we’re quite biased here because we only see when things go wrong, we don't actually see when things go right, and again you want to look at the statistics. Isn’t it something like 75% of them do go okay?

I Yeah, it's certainly the DWP’s argument, is the vast majority of them are handled well. But then it’s the same if you look at the appeal rate and what that works out to be in numbers. That's hundreds of thousands of people. And they're the ones that have actually gone on to appeal, not including the people that have dropped out.

P No, absolutely. I tried to calculate it once, I think it’s something like 8% I think, but it could be wrong. Because actually a vast amount of people that do drop out decide to reapply.

I It's tricky to follow the figures, so I have got a spreadsheet somewhere, because my maths isn’t good enough on its own [laughs].

P You see maths really isn’t my strong point, you know, so good luck with that one. Do you do statistics as part of your degree?

I No, this is why I'm doing qualitative interviews.

P [Laughs] Ah I see! Clever girl, clever girl…

I You’ve gotta play to your strengths, haven’t you?

P Absolutely. I mean I’m throwing out numbers, I haven’t got a clue if they’re right or not, but they sound good, don’t they? I decided that maths wasn’t for me, which is great really, because I decided maths wasn't for me and now, I spend all my life doing benefits calculations [laughs]. And actually, I can do benefits calculations, I’m alright on those…

I Yeah, and the question often at school, is you're sort of like, oh, when am I ever going to use this? And now you're doing benefits calculations.

P Yeah, I always say, oh I don’t do calculus and then my husband, who is quite clever will say actually you have, and I’m like oh shut up. He’s got a degree in physics and psychology, so I don’t really like talking to him about those things…

I That is a power coupling isn’t it?

P Yeah it is, you wouldn’t really think that they go together would you.

[ interview moved into informal conversation and ended shortly after]