# Rupert 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 22 June 2020. Rupert was a Welfare Rights Officer for a sensory loss charity in Scotland. The transcript and written reflection have been anonymised, with identifying names and places removed, or replaced with pseudonyms.*

## Written Reflection

**AR6 Reflection**

Deafblindness is a condition which affects people in different ways. It is an invisible disability. Some may use long canes, dark glasses, hearing aid(s) or have a guide dog. However, many do not. Even if they do use some of these aids they are not a cure. My colleague and I have supported many claimants with a sensory loss to appeal for PIP (and also ESA). We’ve had a few where it’s been deemed that these aids are suffice and therefore the claimant does not meet the points to be awarded the benefit.

There is a common thread of the claimant needing to prove they ARE impaired, and they DO need support despite their appearance. These claimants usually have strong medical evidence which we feel is outweighed by the questions/answers of the panel. PIP awards can be further impacted if the claimant works.

One case comes to mind where many questions were asked how they could still perform tasks with a visual impairment, what adaptations had to be made. The client felt almost punished for trying to stay in work and having a sympathetic employer.

Where someone who is sight and/or hearing impaired it’s ‘easier’ for daily living elements to be awarded but for mobility is it much tougher. There is some case law which states being visually impaired should be treated as a mobility issue due to the reliability of their sight to move around safely. Despite this, it is still a very difficult for someone who has a sensory impairment to be awarded enhanced or even standard mobility.

Another hidden disability which a great number of our service users have is mental health. Again, this cannot be seen and may be harder to ‘prove’ where it is as a result of their sensory impairment (a new condition) or it is a chronic condition they self-manage. As stated previously, they may have medical evidence including prescriptions though even this won’t result in an award if the panel feel they are coping well at the tribunal.

As a welfare rights officer/advisor we are well versed in completing the paperwork before an appeal and as such find it an uphill battle where the medical assessment so poorly reflects the claimant who we’ve spent at least 2 or 3 hours with. At times we are challenging every question as their sensory loss and/or mental health affects all parts of their daily living/mobility. We worry how this may come across to the panel. Are we being ‘greedy’? Will this put the claimant in a poor position for their appeal?

The anxieties of a tribunal start long before we support the client at the appeal and encompass all parts of this stressful process.

## Interview Transcript

I= Interviewer P= Participant

I So if you could just quickly confirm for me that you've got the information sheet and the consent form.

P Yeah. Yes. Yes.

I And you're voluntarily participating in this study.

P Yes.

I That's amazing. thank you. So, I thought, just to get us started, if you could just sort of give me a bit of your background and how you ended up working in Welfare Rights?

P Sure. So, um, I started working at [sensory loss charity] in 2017 as a trainee Welfare Rights officer. Before that, um I'd had a few jobs, I was working, kind of, part time in a cinema as a supervisor, and also part time as a sign language interpreter at college. And so, when I saw that job come up and it was fulltime and because it was [a sensory loss charity] I still get a chance to use my sign language. And, and that's why I took it on. I wanted a job where I was helping people and I never really had any experience about welfare rights but then, obviously, they were going to train me up so that was fine and I'm still there at the moment and I've kind of gone up from a trainee onto a welfare rights adviser.

I That's really good. I've not heard of there being the trainee positions, that seems to be a really good way to crack into it.

P Yeah. I think it's because it’s a voluntary organisation and that's kind of like a point, obviously, and you know, money wise, but because my post is funded through grants. So, with the funding, at that point I guess that's what they could get funding for, but they have been very successful at being able to get more funding so, I think it's quite lucky to still have funding obviously for me to still be there at the moment.

I Yeah, and I think that's the trouble with a lot of, a lot of these roles and certainly Welfare Rights especially is the funding part to keep it going.

P That’s right yeah. And because of the funding sort of, the funding at the minute I can't be furloughed because of the funding agreement, and you know, it can’t be funded by the government. So, but which is okay obviously because then we can still provide that support, of course it’s not the same but at least [audio broke up], which is really good.

I Yeah, I guess it's been a bit of a challenge still trying to provide support for people over this medium because I think everyone assumes that online is accessible, but it isn't necessarily.

P Especially for people who are Deaf/Blind and a lot of people, because they have acquired their sight and their hearing loss. There's just, you know, to get into users now would just be impossible, and we do a lot of home visits so that's, you can't do that at the moment. And we're trying to look at how we can start to build that back in. Things are changing but, yeah, it is fairly different.

I Yeah, I know there's been a lot of stuff about people saying with face masks as well, just how difficult that is for people that are trying to lip read or get any cues from people's faces. People don't, don't realise without…

P No, that’s right. And a lot of people can lip read, if they've been deaf for a long time or didn't realise they had a hearing loss, they are picking up things through patterns. There’re some places I've seen they've got like the clear section in the middle, but you know it's very rare to see that. And obviously some people, they might use a form of sign language called tactile sign language where it's given on the hand, so, we've had taken a few people to make cloth masks… [audio broke up] we have communicators that go out in community and homes and to help them with their shopping and help them and guide them outside, most safe appointments… [audio broke up] have the guide wearing gloves to give that communication you know, but they'll lose some of that touch. So, no signing, no hearing and then to lose that other kind of sense of touch, you know, has been quite difficult for them to get used to. But at least you still have people coming into the house, able to give them that if they have the PPE to do it.

I Yeah, because I think that's especially, I think it's missed in a lot of the government guidance, how, like shielders I think have, particularly been sort of left out of a lot of the information, and it's very individual, so like you've described several different types of impairment that could impact in different ways. So, you need sort of organisations like yours to be there and respond to those individual needs.

P Yes. We are very specialised that way.

I So I take it because you've stayed there, that you quite enjoy your work?

P Yeah, I guess, I was quite surprised I did enjoy the welfare rights side of things, um it has been a lot to learn, obviously, and it's always changing, but I really like going out to people and helping them with things and they come back to us, you know, in that relationship you've already built up that you can then assist them [with] something else. Whether that is taking them through whatever the process they have, and in order to progress here. We've had quite a few people who have had PIP and come back to us again, when it's come up again, so it's been good for them to know, you have that point of call. I think it's very difficult for people to go straight to a CAB (Citizens Advice), for example, you know, it's just, they don't have the money to get interpreters and that's not to say that we do, but I do have a certain level of sign language but then I'm not an interpreter, you know, it's not the same. Um, if they did need something more specialised, we could maybe ask one of our communicators to come out with us, which we do sometimes, um because just like with any language you know, people may have their own variations of the sign language, and you know, they might have family signs, for example, and to have a good communicator whose so familiar to that that person just makes that much easier in order to then go into quite a lot of detail about, you know, to do a PIP form for example, you know, which … can be quite nerve wracking at the best of times. And so yeah, we, you know, to think about all these things.

I And the PIP form itself, other than the emotional part of trying to fill it out is, it’s also really long. So, yeah, time consuming as well.

P Yeah, that’s right, so we'll be at somebody's house I’d say for at least an hour and a half to two hours. And that’s not completing it that’s only taking notes. We just, they have the form, we go through all the questions, take notes, get them to sign that page, make sure they understand everything, if they’ve got any evidence and then we'll go back to the office and start handwriting it, obviously, and make sure we have… because you just have to make sure you have everything in it and you get another copy to do that so, we really do take a lot of time to do these forms, you know, you can’t do them quickly and I think unfortunately sometimes when we do go to, you know, it’s them coming to us saying ‘oh I've got an appeal, and I was just so surprised there was so little information in the actual form’, and initially… it's just, we can see how they weren’t awarded because the actual detail isn’t in it. But then, of course, they don't realise how much information is needed that, that being the person who's actually trying to apply for PIP. They just think oh, you know, because the question that's asked can be, it can look quite straightforward, but that's not really what they're asking, you know, doesn't lend itself well to be, to have the whole page completed, for example.

I When you first of all, get people coming to you, they sort of already involved with the charity, maybe or is it someone sort of coming fresh to you possibly?

P So it's a combination of both, um, we have members here so they can have any degree of sensory loss. But a lot of them wouldn’t fall under the PIP criteria for age, really. So, as some of them are, and they would continue to go through us, but some people are referred from other [sensory loss] charities such as [name removed], and [name removed] helpline sometimes refer them to us. We also have charities like [name removed] and other sensory loss charities, we are getting quite well connected with and just, and some people it's just through, ‘oh my friend, you helped my friend’ and then sometimes we have to, you know, because of our strict funding, you know, we have to ensure that they have at least a single sensory loss. We're happy to help them if they have, you know, say, sight or hearing loss. And as long as they have one of those then that's, that's fine, but a lot of them are through [sensory loss organisation], because they have inpatient support at the hospitals. So, somebody could just have a diagnosis, or they could have been just registered partially sighted…And, and that's been, you know, they’ll go through that with them, many different things. I don't think it's a very long appointment, but they seem to go through a lot of information with them and one of those is to do want to get referred to us, and that's we will then contact them.

I And do you find it sometimes quite difficult sort of getting information to do the PIP form because it's quite personal isn't it?

P Do you mean like, when we go to the house, and when we actually do the form?

I Yeah, if you could sort of take me through your process and sort of how that that works out.

P Sure, so like for instance, if somebody… we had a referral for somebody who met the criteria for PIP, um, we would probably, we would ask them to phone up for the form initially because obviously we can, we can’t do that. Then ask them to give us a phone back when they have it, and we’d then get them an appointment to go and see them and usually that's in their home, but I’ve met people in cafes or in a meeting room at their office for example. Um, then we just go through the form and really have a think because, I think at first, from my manager who's been there for quite a while, she's been doing it since 2014 since this project started doing welfare rights. We have a lot of kind of prompting questions. So now when I'm going through it, that's just second nature to me and I don't have to think about it too much, especially because we are so focused on sensory loss, depending on the questions, they'll be a lot of different things that I'm looking out for. Um, and if they haven't said that I'm definitely going to be asking, you know, could you manage this? And can you tell me how you do that? And, do you find that you can see this as well? Or, you know, even things like, you know, how would you run a bath? You know, because obviously I know, it’s a clear liquid and I know that if you were to fill it up, people don’t think about it, they're like, ‘ah I just put my hand in and when it gets to this point I stop’. But of course, I need to write that down, otherwise, somebody who’s reading that PIP form is like, so they can run a bath and can get in and out of it fine. You know, and there's a lot, we have a lot of prompting questions in that way to keep going on and saying, and then usually there’s something and they go, ‘oh I sound really terrible, I sound like I can’t do loads of things’. And I'm saying that that's not the case, we’re just showing how you've adapted so that you can manage yourself, or how somebody does something so that you can still do it yourself. Um, it's not to say, you knowm that, that you don’t have a lot of difficulty. They say, ‘oh I’m fine, I’m fine’. It doesn't mean it’s not a struggle for them. You know, maybe it takes them several steps to do something and, of course when they're talking, you're just trying to pick up those things and make small notes so that you can go back to it later. Um, but obviously if there's somebody else there, like a partner, you know, and when there's children or something. Sometimes they'll say oh, you know, they said something then the other person will say, ‘oh, but that's not true’. You know, because this that and the other so, I'm always trying to take both, you know, way up and not shorten and show it in that broad strokes, you know, sometimes it's okay but, you know, sometimes you do struggle. And, you know, it's just to try and get that full picture. And because obviously people are quite positive, we all are, and I always say to them, you know, these questions are hard and if you were to ask me, I would be struggling to answer too, because you don’t think of it that way, you just do it. And so, we just really take our time with it and if they need longer, because we always have at least 2-hour appointments in our calendar, so it’s not any rush from us. And, of course, I appreciate you know, for them going over that form for two hours can be quite draining. I think that's why it's good to have it in their own home if they want, because then they feel comfortable. They take their time and not worry if they get upset or they want to have a break themselves, because that's, that's okay with us. And so yeah, I think… I think because we're quite experienced at this point ourselves, it's, it's not too bad for those to complete it, to know what questions to ask.

I Yeah, because it helps with that, that sort of experience, you know exactly what you're looking for.

P That’s right, that’s right, absolutely.

I It sounds like having a partner, or a child, or a friend sort of there, makes quite a big difference. Have you found that?

P I think so. I think it's a funny one because sometimes it can actually hinder it. It really depends who it is. Sometimes you don't actually hear the voice of the person you're there to see and the other person takes over. And, you know, sometimes you think, well that's not really, if that's not what they want to say, then that's not what I want to write down, um, because that's not how they would fill it out. So, um, it just really depends on the person, but I think on the most part I would say it is helpful, because you know, you're getting that, that other view not just somebody saying ‘oh I’m fine, I’m fine’. And if you have another person saying, ‘oh, but remember I help you with this’, or, ‘I usually stick your clothes out’, or ‘I'll tell you what colour it is’, or, you know, things like that and they don't really, because they think, yeah they’re fine. You know my clothes are there, I put them on. Um, just things like that, I think, for the most part it’s quite helpful, because, especially, you know, you can see wee looks from the person and they’re just shaking their head, because the person can’t see or hear them well, like that's not true. They’ll say ‘oh I’m fine’, that’s not true. You know, if it’s a yes or no, and sometimes tick box, then I can go through that with them, say ok you're saying yes, you're saying no, how would you feel if we ticked sometimes, for example, so it's just trying to take full picture again.

I So I know from, from what you'd sent me so you're, you're sort of working with people that often do have that sort of medical evidence. So just wanted you to maybe sort of, tell me about how that works out and what impact that has on their applications and the whole process.

P So I guess we have people who have, we usually try, if they’re able to, to get like their medical records from the GP. Which is sometimes easy, sometimes not, sometimes they charge and sometimes they don’t and it's just, you know, obviously I can write in on their behalf. I usually have consent for that, so its ok. But usually, a lot of them are registered, either partially sighted or blind, so they'll have their certificate um, so we'll include that and maybe any letters of diagnosis from, you know, consultants, because quite a lot of them, they'll have other conditions, um, that we're talking about as well so, really just try and get everything we can and encourage them to have that medical evidence. Um, but like I’ve said even with that sometimes, and it can seem quite strange to me that, you know, it's not kind of weighed as heavily as what we think it should be. You know, if somebody is registered and has that medical certificate that consultant ophthalmologist says, you know, you have a sight impairment to whichever degree, you think that would correspond with the point system but I think, you know, if you look too good, you know, ‘oh you can manage’, then it doesn't matter what that piece of paper says, and just about… which is, you know, it doesn't really make sense to us.

I Have you found that sort of what people look like and how they, they function, makes a difference?

P Yeah, I'd say so, I think, because I would certainly think for some people their visual impairment, they've adapted so well to, um, especially people who have had it maybe all their life or for a long time. It's almost like, like we all do, um, you know, you just don't realise how severe it is because you’ve adapted so well. You know, so you're able to sit in the waiting room and get up and just go straight on through, um, without having to take somebody's arm or use a cane and have anything like that so, you know, it doesn't mean they’ve got the full picture. If, quite often they have the confidence to go with that, um, so it can put on a bit of a, you know, you know…no, not like a false persona of themselves, that’s a bit harsh, I can’t really get the word straight, you know, it's not really, it's… I mean they're not struggling they're just, they're just managing as best they can, as we all do, but it seems to go against them. Certainly, because of that.

I Do you think, oh, no, sorry you keep going [cross talking].

P I was just gonna say, um, I was thinking of one of my colleagues who has, he’s deafblind and, and, well, because I've worked with him for nearly three years I can tell that his sight is deteriorating because of the way that he moves but when I first met him, you couldn't really tell that he has a condition called retinitis pigmentosa, which means he's got peripheral loss, so he's only got a bit of tunnel vision left. So, if he's looking directly ahead at us, it's perfectly clear, he can see everything. But, so he had more vision before, so he could move around quite confidently and knowing his surroundings very well. So, especially if somebody was to say do a home assessment, not that…they would mostly be in the one room. And, you know, they know everything very well, but it doesn't mean they can see everything. But it's just that, you know, it's just that thing of, if you're seen to be able to do that, then that's okay, and especially if they're to do, um you know, the eye test they have with the chart. Well, if that person has perfect clear vision in the centre, they could read that perfectly, but if they were to move that, they just couldn't see it, you know. Um, and it's just to trying to get the other person to understand what, what that is. Um so obviously, that person you're meeting may not have any understanding of sight loss, for example. So, it's, it's quite difficult to get them to appreciate just in a short space of time that you've got with them.

I Yeah, I was, I was gonna say, if you found the expertise of the panel to be sort of part of the issue there with understanding what these different conditions are actually like and what they mean?

P Yeah, I would say so, um, I guess like there was a couple, there's a couple people that I was thinking about when I was completing that and then obviously my colleague kind of put her experience in as well so [referring to written reflection]. They really…they really, the panel don't like, I think, if you say you can go out and do things. And then what I would call is, you know, I guess, you know just living your life and that whole like life experience that you're supposed to live it to the full. So, if you say… I had this one gentleman who went down in the water, to one of the local coastal towns, but with a friend, he was assisted the whole way. But then, they're saying, ‘how can you go down there?’, ‘how can you do that?’, ‘how can you go on the train?’, you know, because he also, he had his sight loss, but he also had a physical disability as well, the whole time and was in pain with it, but they're saying ‘how can you do that?’ but the sad thing of, if he felt up to it that day, why shouldn't he go down there and have that and have that be part of his, you know, relaxation and then help his mental health and, you know, they're kind of saying, oh, you know, it's somebody who's against you.

I had another gentleman whose partner had a brother who lived in Thailand, or the Philippines, I think it's Thailand and I was so worried I was like; this is…they’re gonna grasp onto this, the panel, it’s gonna against him. And, of course, this is what they kept asking, ‘how can you go there?’, ‘how can you get onto the plane?’, and he, you know, was obviously getting very agitated. He's like, well, ‘I had passenger assistance, I got wheeled onto the plane, I got wheeled off’, it's like, and he even had to say like, ‘look, my brother-in-law picked us up, and I just stayed in the house for two weeks’, it was mostly just for his partner to have that support of him, yeah for him to go somewhere else but not really expedience like you and me would. Um, and also you know, in order for him to support his partner to go abroad to see her brother, but then to get that, because they're just thinking you know, you can just go get on this plane and get off and go on holidays. On your benefits, you know, and the guy’s like ‘my brother-in-law paid for everything’, you know, he shouldn't have to really expose all that yourself.

I Yeah, it's a lot of information you've got to give to prove why it's okay for you to get on a plane.

P I know, it's just it's just, …. very demeaning, I guess, you know, um, but we'll always get anxious when they say, ‘ah I’m gonna be doing this’ and you're in your head, you're like, oh, don't tell anybody. You shouldn’t have to think that way… we shouldn't have to say no, don't tell them how you live your life because it's gonna go against you. And sometimes, what I do, you do have to say just to remind them, you know, tell them how, what support you had. And that's where, I mean, I think, I don't really speak very much at it, we put so much into our paperwork that, you know, we don't have to add anything but we will prompt if we need to, you know, just say, can you clarify how, you know when we spoke about how you did manage to do X,Y or Z. Um, you know, because obviously we can’t say, oh that's not what you said, you know, you have to be so particular about it, and so I think in both cases, the two cases I'm thinking of that I did myself, we were lucky to get an award, but I was very anxious about it. Seriously, and you've probably heard this before that, sometimes, you know, they will ask, you know, ‘where did you park?’, ‘how did you get here today?’ and um it’s quite good myself, and my colleague, that we both drive and we're able to take people from their house to the tribunal place and we've got an organisational blue badge, so if they don't have one…

I Oh that's really good.

P We’ll put it in the car, and we do our best because, you know, they would be eligible for one if they wanted one. So, you know, you do, you do worry from the very start of it, you know, how is this gonna come across for them? You know, because I think one time, I even saw the judge outside, and I thought, you know, you just think that he looks kinds like, he could be a judge. Um, I think this guy, he did use a couple sticks or something and it was all legitimate of course, but you’re always just, you know, you’re always thinking about things and probably analyse and over-analyse how things could look.

I Is that something that you're, I don't know if you call them clients or like is that something...?

P We kind of mix it up that's because some of them are service users but some of them aren't, so that we can just use the broad term of service users, even if they're not actually a member of… and so, yeah.

I So if that's something that your service users are sort of aware of, from the process as well.

P I would say so. Um, I think they do appreciate that, you know, how things come across. And, and it's, especially because by that point they've had an assessment and that assessment’s come back saying something, you know, that doesn't reflect them. But if that person has said, and has had the evidence to support that they have mental health difficulties then in the assessment and they've said, ‘oh, presented… they had clean clothes on’, you know, ‘he didn’t look anxious’ and most of the time I've supported that person to that assessment and I know they have been anxious and I could say, oh, you know, if, if, you know, they rattled on about bit something because of that anxiety, it doesn't mean, you know, doesn't mean that anxiety looks a certain way, but I just know from even spending that short amount of time with that person, that's not their relaxed self. Um, so they know how that's gonna look at that point. So, yeah, they get worried about that, and we talk through that best we can just say, you know, just have to be yourself. Um, because that's what you can, just if you go in and lie, you know, it's not gonna work, because they're going to poke holes in it, so you might as well just be honest from the start, and just see how we go from there.

I So it's interesting that you, you sort of see both parts of it, so the assessment and the hearing as well. Can you just take me through sort of like what your, your experiences of that have been and how they compare to each other?

P Yeah, so sometimes we'll have people phone up and say ‘oh, I've got it back and I’ve not got any points or, you know, only got this or….and it's just, it's unreal because I know, like I went with them and sometimes when I was sitting in there I’m like taking mental notes of, they asked this or they wasn't really paying attention when they said that um, you know, of course, I think with the assessment is a bit more leeway. They will ask me at times if you’ve got anything to add, you know, it's just very dependent on what the assessor at the assessment is like. There’s at least one or two people that me and my colleague both kind of know, um, because we’ve been to so many assessments now that, that person doesn’t want to hear from us, you know, we're basically not there. Um so, we’ll know not to say anything because they can get their back up quite quickly. And we know it's all about, it's all about that person, it's their assessment so we're there to support them as best we can, of course, so we’re not going to do anything to jeopardise it and but some of them are very, very chatty and they want to hear from us and… which is quite strange at times because we're used to just sitting there, not really saying anything. But yeah, so sometimes when it [assessment report/decision] comes back you think, oh god it’s almost like a completely different person. It's not the person that you know because I was there as, yeah, I'm not… I mean I'm impartial to a degree because, you know, I do have that person's interests at heart and I want to see that and I do think that they are eligible otherwise we would say to them, you know, we're very honest with them we say, you know, don’t get your hopes up too much and we think you could get this could or could get that and you know, we never promise anything but we do our best and… and so, it's just really strange when it comes back and it's several points for say, you know, preparing food. And you know, we've said in it like they live off microwave meals or, you know, only use a microwave and can’t chop and it's just, you know, they’ve said all this and it comes back and it's, you know, and especially it’s the same when, you know, and they say, ‘oh, he seems fine’, ‘he seemed relaxed’ and you know that not to be true. You just, I understand they're under a lot of pressure, but it's just so strange that it'd be so different.

I Is that something that some of your, your service users will say as well that it, it seems odd to… and not like them.

P Yes. Uh huh. They get quite, quite… they can get, not upset as in crying, but they do think but how can this be because that's not what happened. So, it's almost like it's against them from the very start. Um, because they go in and do their best and are honest with that person who they don't really know and have to tell all these things to again, even though it's in their form. Um, you know, so, yeah, it's upsetting for them to read that know that's not true. And then for us to say, oh that's unfortunately that's common and we're not surprised. Although we, you know, we should be upset as well but we're almost like, ok but let's go on to the next stage now because… and some people, we've not had many, but I know one person who, she had the assessment and even though I said her several times, tell me when you've it, I’ll go with you, she didn't, and of course that went against her because she said, ‘oh I've got public transport myself here’, and of course they’re gonna be like oh right you’re fine. And then she didn't want to go to appeal, she's like, ‘it’s too much I don't want to do it’. So, it's a shame because I knew that she was eligible but there's just too much…

I Yeah, it's that. How does that, that sort of difficult experience with the assessment, sort of impact on people wanting to appeal, or how they sort of view the process going forward?

P Yeah, I guess, to just think that the odds are kind of stacked against them for that point but for some of them, it can kind of like spur them on and say ‘well no, because that's not true. And I'm unwell, I'm eligible and let's keep going’. And some of them, you just have to, you know, we obviously respect them and would never push them into something they don't feel comfortable with but, but we do have to explain the whole thing of, you know, sometimes this does happen and it's not uncommon and, you know, we think you're eligible and it doesn't reflect who you are really, because you don't have the points for it. You know, they have that timeframe, so we let them if they need it and if they want it, they can have, you know, a week or something to then get back to us and we'll help them with the appeal. I mean I've had a couple people, and even not for PIP but for other things and say I’ve had a think about it and I'm gonna, I'm gonna appeal it. So, yeah, it can take, take them a bit of time to come round to it, because obviously that's a lot isn’t it, to know that… you say it’s a tribunal and you say it's a judge and they think, ‘oh, God’. And really, that's honestly, that’s not what it's like and we can explain everything to them so… um I guess it’s and that’s where it’s good that they've had that relationship with us to know, one of us will be there, and we've had the experience of doing it, um, and they'll always have, you know, me or my colleague that we could jump in and help the other person’s service user so they always have that support going through. And I think that, I think that does help them because I know if that was me that would help me a lot to know, to have that consistent… consistency going through. And so, it is a very anxious time for them, understandably.

I How do you sort of help them when you're, say in the waiting room or like just before explaining the process, because I think as you said there, what we think of a tribunal and a judge, it's very different to what it's actually like isn't it?

P So even, I would say, once they said they want to appeal, even at that appointment explaining what happens. Say, you know, it's a panel and there's a judge and there's somebody with an understanding of disabilities and, um, you know, there's another person there, and then, you know, it's just a room and a table and two chairs and we'll go in and they'll just ask more questions and things like that and I think, from, on the actual date, or I think even the day before, a couple of days before them I will call them back up again and, you know, say how you doing and just kind of do a wee kind of a call with them to see how that's going and then just reiterate, you know, I am picking them up at their house at this time. So just to put them kind of at ease again. And then when we pick them up, um, just because obviously we have that car journey however long it's gonna be, how are you doing? and are there any questions you want to ask? and… then for that point, depending how long it is, you have a wee chat, talking about their family, just like normal and, you know, what's going on and you can just have a normal chat with them and just kind of because obviously, sometimes we'll be feeling a bit anxious as well and we want a bit of a distraction so…

You know, and so when we go in, we can just carry on that conversation or just try and talk about something else in the waiting room, depending on how busy it is and also depending on how their impairment is, we might have to give them that environmental information of, oh we’re in a room, the chairs are set up like this and there's this amount of people in it and because we are, you know, we’re both myself and my colleague, we’re both trained in deaf and blind guiding, so guiding communication, so we know, because we're so used to helping our members in the centre, so we know, and because we know them quite well by that point we also know what they need. I’ll say, do you want me to tell you, we can just do that and it's just normal. And so then, obviously, when we actually do get called in, if we’re guiding or not guiding, we’ll still say, oh, you know, that chair, or just go to that chair or whatever. We’re quite conscious of all that and how it's gonna be received by other people. Of course, just trying to keep them calm, make sure that they feel comfortable, as much information as they want and just letting them kind of direct the conversation because they might want to talk it, or totally not want to talk about in this vein. Just taking their lead.

I Do you talk much at their hearing as well or is it just trying to sort of support them to say as much as they can?

P So, um I think only… I've only spoken maybe once or twice at them and I've done a few but, I think mostly, it's me, prompting them to reiterate something that I think they've missed or I always get asked at the end, ‘if you’ve got anything else to add’, you know, any like case law or anything but I put that all into the appeal papers so there's really no need to add any of that, certainly there’s never anything that's been so new to come out that would support in our case anyway. So usually, I don't say anything. It just depends really but I would say normally not, just there to support for… just to be in the room and know that I'm there. Because sometimes they’ll look at me and say, one of the guys I was thinking of, he was just so chatty when he got anxious, he just ran on and on. So, the judge would always have to say, ‘okay, let's go back to this, because that's not really what we're talking about anyway’. And he would always look at me like, as if we're all having a conversation but of course that's not the case. So, just whatever helps them, you know, that's how it is for them to get their point across, and that's it.

I How do you find the panel sort of with your, your paperwork is it often they've, they've read through it all, or can it be a bit inconsistent?

P No I would say they always read it. Yeah, and I would say, we're quite lucky, it's very detailed and I don't know if that means it's too long, I'd rather it be that way than it's no good, to make sure it’s done thoroughly. I think our submission to the court, maybe it's at least at least two pages, sometimes it goes to three, but I try not to let it go over three. Um, and that's the thing I think I'd say, is that sometimes you can ask, you know, there's people who fulfil criteria for every single point. And I do have that thing in me where I'm like, if I ask them to look again at every single point on the PIP form, is it is just, is it gonna look like we’re being greedy, is it gonna look like we don't understand how this PIP form works? That we’re like oh we just contend everything…. You know, we just wonder if that puts them like, ‘ah they’re asking for everything and they’re asking for x amount of points that they can get’. And so, we do get a bit worried about that, you know, so obviously they're reading that and then have that in their head and then we’re coming in for the appeal itself so... and of course myself and my colleague, we're very conscious of the fact that we're gonna assist more people at this, um, to these courts so we also need to make sure that we've put ourselves in a good light as well, to help future our service users so that we've got a good reputation. I don't want to have that reputation of the person who just asks for everything, because without meaning to, that could really go against future people which we wouldn’t want obviously.

I That seems like quite a tough thing to balance, sort of, given what happens with the assessment report as well where potentially you do want, and could challenge, every single point?

P That's right and I guess some people say, oh, you know, I've given it before, or got that many points for reading before so we'll just leave it at that, even if we could maybe push for more. But, you know what it's not and I mean I would always explain it with them, you know, are you happy to say this, say that so they know exactly what's going in. And I think it can be seen, I know for me it, the first time I ever saw was it was well, how am I gonna fill this in myself, you know the submission to the court, seems so daunting. But when you break it down it’s not too bad, it makes a lot of sense. And because it's not a form really, it's just, you know, us breaking down our points and getting that across. But yeah, definitely, be definitely… be that sometimes, I don't know if they read it just before we come in or what. And to say about the assessment as well so we've had people, because ours are so detailed, um, we've had people, we've actually been a bit delayed because they've still been reading it, I don't know when they get it to read it but…um. Makes me think that they'd just read it just before we come in for the first time almost but, yeah, I don't know… a good or bad, there’s a lot of information in it.

I Does that, sort of, need to put more information in, is it sort of a bit of a safety thing?

P Oh yeah, because I think it's that way of, that outlet, talking a bit before is that they don't realise that they do things a certain way. So, we have to put that in otherwise, they're not going to say it, but I thought if an assessor, or the judge said, ‘why'd you say you do this?’, they're going to come back and say, ‘oh yeah, that's true my partner does this’. Because it's true, but they just don't think about it that way. And we have very few people who, you know, will talk about it in that way and give the assessor or the judge exactly what they're looking for. Because, if maybe they’re going through from DLA to PIP and they know exactly what to do now. But definitely yeah, we have to, I feel like if it's not in and if they're not, maybe they wouldn’t even think about saying it to the assessors or judge. And so, we would definitely put something and that's why there's, all the questions are filled up, there's sometimes additional sheets as well with their evidence so, yeah.

I Let me just have a quick look back on my notes. So, in your, in the reflection you sent, I think you've touched right now as well, is like when people seem like they're doing well that kind of goes against them. And, in particularly at the tribunal if they're doing well, I just wondered if you could give me a bit more about that and what your experiences have been.

P Sure, it's just for people who say, oh, maybe they have like their aides, you know, whether that be, you know, they've got their simple cane like that's the short cane the white one that just shows them, or they’ve started long cane training, so they've got some mobility training from, say, the sensory impairment team at the council or through Visibility, they do rehabilitation training as well. Or, you know, things like that. Or maybe that point, you know, they’ve started to receive maybe counselling or attending team support groups, or something, you know, so if they seem a bit more positive say than other times. And, yeah, it would just seem like, oh, well, you know, you've got good support now and you've got all these things going on for you. But it doesn't mean, I guess, it is that thing of you want to be positive, you want to say how well you're doing, you don't want to, you know, that’s why we say think of the good and the bad days. Because, um, you know, and I guess sometimes they do ask, you know, they definitely ask in the assessment and they might ask at tribunals, you know, how many good versus bad days would you have a week and for them to be honest about that. Because, because…that's their one point, to get that across and if they don’t it’s kind of missed, you know, it's always harder, it's always harder to get that back in, you know, in another appeal. For example, if it doesn’t go well at the assessment, if it didn't say it in the assessment, it’s always harder to get it onto an appeal because they say ‘oh you said you were fine, you said you could do that’. And especially if somebody else filled it out, or if we did fill it out, we went through it with them and it was definitely what they said, you know, it’s not embellished at all. And then they, say at the assessment ‘oh no I’m fine’, which is so frustrating because, yeah, we spent all that time doing that for them, but we just know for them that's, that's not, that's not their true selves, day to day. Um, but it can be hard, obviously like we've said before, for people to open up straight away to people, that’s why I appreciate for us always good to see people and in their homes it's not easy, for them to just give us all this information, especially if, you know, some people still can't believe all these things have happened to them. All you do is, do them justice in their form to make sure it does reflect them properly, um, but yeah, I would say, it's always something to think about it. How is that gonna look if they’re having a good day? Yeah, and then it's just so dependent on the person who reads it, you know, are they gonna… they're having a good day, or are they going to be honest and say, ‘oh I think they were a bit anxious and I know that because they were doing this, that and the other’. So, it's just you just don't, you don't know how it’s gonna go, you just can't tell, you can always just make sure the service users understand what they're, what they're getting themselves into and, you know, the process and if that doesn’t go how you would like.

I Have you found the panels are generally quite good at getting people to open up to answer questions like that?

P No, I’m gonna say no to that. I was gonna say that… the judges almost, it’s just like this one judge just sticking in my head it's like I guess how you would imagine a judge to be you know, very direct, ‘so you're saying this’, and then just cutting them off and you think, oh if you just let them speak a little bit longer, you would have actually caught the information they wanted to give to you but… And, you know, I can see from myself if that was me sitting in that seat I wouldn’t feel, I wouldn’t feel confident to give that information. Um, I think it just really depends who the other two people are in the panel and how they all go together, I don’t know how they decide that, but because there should be at least one person who's maybe empathetic to them, and kind of getting them to open up. Sometimes it feels like they're all against them, no matter what they say, they say ‘oh so you can do this’ and, you know, ‘you went on this trip’ and, you know, they sometimes seem to focus on something and it just totally takes away from everything else that they want to talk about and that's so easy to, you know, you have that small time to have the appeal and then you just spend it all talking about how this one person went on a trip. Um, and of course that can just, you know, frustrate people on both sides of the panel. But, yeah.

And I don't think there is... And obviously, we've had a couple where somebody else has been nominated to speak on their behalf. So, I've heard about that before. One of which I know about, um, I think this maybe because one person was autistic and the other person had some other like learning difficulties, processing issues and, and that can be very upsetting for both, both parties to have to do that and that was my colleague that did both of those so I don’t know how… I know, in the end the award they were successful, but to have to go through all that, and it's just terrible. Obviously, and it's just, I just know from the ones that I’ve been in, the judges haven't really given them the space, I think, they need to talk. Because if you in, I think they go on quite harshly, so then they could just shut down and not say what they need to.

I And that seems like that would, that would really make you clam up, wouldn't it, if someone's like that and it's not open?

P Yeah, especially if you're, if you already know from that assessment initially, ‘oh, they don't believe me’, and ‘I've said all these things, I've given all my information and they still don't believe me’, and then they're going to the appeal and they're still acting as if they don't believe them. And they have to prove… honestly, I can't see properly or I can't hear properly or I have all these other conditions and everything together, is impacts our life severely. And, yes, it can make them, just clam up sometimes, um, like the one gentleman who just anxiously kept talking and talking, I don't know if they would have got all the information if he wasn't so anxious and he didn't just keep talking. And they know, they got some bits of information but a lot of that, they didn't really need it, didn't really help him but at least you know, in a way he was, you know, talking. Yeah.

I Is there sort of anything else that you want to talk about or that we haven't already gone through?

P I don't think so, obviously I just had, you know, like I'd say for people who are deafblind it’s a massive spectrum so…um so, I think, I can’t, I think we've been maybe lucky as in some people who are like, maybe born, deaf and then lost their hearing and then have used the deafblind manual, so they’ve maybe not had to go to a tribunal but then still be asked to go to appeal, sorry… to then have to go to the assessment, you think, on paper like they’re not going, it’s not going to get cured at any point, how it's gonna be so... so then, for some people, you know, varying degrees and still have to go to appeal. I think, I think maybe one once or twice.

I know that my colleague’s definitely had this where the judge has been like, ‘why are we here? Why are we hearing this, we shouldn't, you know it's a waste of time’. And sometimes, we've been lucky to have it, we haven't had to go to appeal but maybe that's just been decided the day before on paper, but it's just not common at all. But that is much better if that can happen and obviously people don't have to go through that, as well. But yeah, it's just, it is difficult, and there's not a lot of case law that supports us, and that, they have a couple things, but it's mostly just about sight and how even if they have sight, it is not reliable and it doesn't…it can't be used the you know as that, that term is reliable and I don't know what the term is, but they have that, you know, and if the judge says you really can't use that and say that is because it's not that sort of moving around. Because moving around is very difficult to prove, moving around’s a bit easier. You know, ‘oh, I can't read my letters’, ‘I can’t do this’, but moving around they say, ‘oh but if you're physically, if your only impairment is that you can't see and hear properly, but you can, you can walk, that's fine’. Of course, you can’t. But then, if you say, ‘I can’t hear the traffic, but I can't see if there's roadworks’, ‘I can't see the bus’ or, you know, here's a bus or, you know, it's very hard to prove that one… so put it all down but ,you know, you’re just fighting an uphill battle because it just, you know, obviously you probably don't want to award a certain amount of points anyway but, and it’s difficult, it’s certainly difficult and we’re all just trying to make sure that we've got latest case law to support people to make sure that, you know, they can get what they can but…. um, yeah. It is difficult but at least we have that experience, and we can, we have like, I have my colleague I can work with, and she has had experience and we can kind of give each other things and what's worked, what hasn't. I just hope in the future things improve but, um, obviously with things moving to Social Security Scotland, and it is very open at the moment of it what that form is going to look like and how accessible it's going to be. And so hopefully that would, if it is good, if it is good for our service users then there might be fewer appeals for him. We don't know when that's gonna to be at the moment, obviously, so yeah.

I Yeah, I think that's the trouble isn't at the moment, anything that was on the cards is now a bit up in the air.

P That’s right, it’s very much delayed. It was supposed to be happening quite soon, and now that transfer it will be…but that's just, again something else for our service users to get used to. Okay, you were on this and now you're gonna have to switch, at some point, that sort of thing, but yeah, hopefully things will improve but we will work with what we have to at the moment as best we can.

I Well thank you very much. It's been really useful.

P That’s okay, I'm glad I could help and obviously it's important to get our voice because it is fairly niche what we do so…

[End of recording]