

Work and Pensions Committee

Oral evidence: Health assessments for benefits, HC 604

Wednesday 16 March 2022

Ordered by the House of Commons to be published on 16 March 2022.

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Members present: Stephen Timms (Chair); Debbie Abrahams; Siobhan Baillie; Steve McCabe; Nigel Mills; Dr Ben Spencer; Chris Stephens; Sir Desmond Swayne.

Questions 119 - 179

Witnesses

I: Tracey Lazard, Chief Executive Officer, Inclusion London; Jane Hunt, Chair, Association of Disabled Professionals; and Patricia Vespuccio, Team Leader, Advice Service, GIPSIL.

II: Sarah Rawlings, Executive Director of Research and External Affairs, MS Society; Jasmine Wyeth, Senior Policy Officer, Rethink Mental Illness; and Catherine Hale, Founder and Director, Chronic Illness Inclusion Project.

Written evidence from witnesses:

[Inclusion London](#)

[GIPSIL](#)

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[Chronic Illness Inclusion Project](#)

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Examination of witnesses

Witnesses: Tracey Lazard, Jane Hunt and Patricia Vespuccio.

[This evidence was taken by video conference]

Q119 **Chair:** Welcome, everybody, to this meeting of the Work and Pensions Select Committee and an evidence session relating to our inquiry on health assessments for benefits. A very warm welcome to the three witnesses joining us for our first panel. Thank you very much, all of you, for being with us. Can I ask you each, in one sentence, to tell us who you are, starting with Tracey Lazard?

Tracey Lazard: Hello, I am the CEO of Inclusion London. We are a disability equality organisation that supports about 70 local disabled people's organisations in London. We are run by and for disabled people.

Patricia Vespuccio: Hi. I am a benefit adviser and I help run an advice service in Leeds. It is a local charity that also has other support. It offers support for young people and adults who are normally needing housing support. There is an advice attached to that extra support. My background is as a benefit adviser.

Jane Hunt: I am from the Association of Disabled Professionals. We support disabled people in work and try to make things better for them. I also help others.

Q120 **Chair:** Thank you very much. Do you think the current health assessments for benefits could be adjusted to overcome difficulties that we have heard about in this inquiry or do you think a more fundamental overhaul is needed, such as starting again from the social model of disability?

Tracey Lazard: We definitely believe a fundamental overhaul is needed. The heart of the problem at the moment is that neither PIP nor WCA accurately capture the needs and the barriers that disabled people experience. It is those needs and barriers that create those extra costs of disability or make it likely or not that you are going to get a job in the real world. The current process is based on very medicalised descriptors that capture functionality such as whether you can lift a half-litre bottle of liquid, or whether you can put your arms above your head.

Functionality is an important part of the story, but it is not by any means the total story. What we need is a process that understands the barriers that disabled people experience, systemic barriers that discriminate and exclude us, and we need an assessment process that captures that.

For example, with PIP we need a process that does understand the extra needs and costs of disability, such as the additional energy and heating costs, which are a terrifying and growing issue for us at the moment. The current format does not capture the extra expenditure of specialist kit.



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That can range from powered wheelchairs that cost thousands of pounds to the need for electric can openers as opposed to manual can openers. It does not capture the cumulative costs of maintaining a home or being presentable.

Whether it is changing a lightbulb, the gardening, the DIY, many disabled people who have support needs will need help with that. The current PIP format does not do that. It does not capture the cost if you are a disabled parent who needs additional childcare, for example. In London there is recent research that shows that the cost of living in London is between 15% and 60% more than other places, and that is not captured.

The same situation is with WCA. What we have is an even more crude functional assessment that does not understand the barriers. For example, you could have a visually impaired person with a significant impairment who cannot drive but is living in London and has a desk-based job. They are still going to experience significant barriers. You could have a person with the same impairment but living in a rural area with poor transport and poor broadband, and their chances of getting a job are significantly fewer than the person in London. We need a process that captures all of that and that is a more social model approach.

Patricia Vespuccio: Yes, we agree that the current model is not working for the people we work with. We find that the descriptors for the work capability assessment seem quite outdated and they do not necessarily capture the whole person. In the way that the assessments are run at the moment, they do not allow people to tell their stories. I am a benefits adviser and what I see is the result of those assessments and those decision letters and they do not reflect how people experience their health and their conditions. Therefore, yes, we agree that a model that takes account of the whole person is what we need.

Jane Hunt: I agree with the participants—I think that the WCA needs to be updated to reflect the modern era. Someone could perhaps try working in a call centre, that sort of thing. It should be tailored to the person, not tailored to what you can do.

Patricia Vespuccio: Can I make one more point? I wish I had said it before. Despite whatever changes you are going to make, fundamentally for us what seems to be the main issue is that people do not feel that their testimony is being believed and their evidence is being given its due weight. That is the main issue with all that we are going to talk about today. Whatever system we are going to have, if that does not change, it does not matter whatever descriptors you have, or however much discretion you give to descriptors. I think that there should be more discretion on, for example, PIP. Not relying on informed observations but believing the person is what is important.

Q121 **Dr Ben Spencer:** I am going to ask a few questions on the medical versus social model. A massive health warning, I am a doctor although not practising, so I am going to come at it from the medical model side. It has always struck me that for critics of the medical model, what it boils



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down to is what I think is bad medicine. Certainly, as a mental health doctor, listening to the patient's situation and hearing the context in which they live and the world they operate in is critical to any good medical assessment. I often wonder if that is what the proponents of the social model are tapping into. Would you agree with that?

Tracey Lazard: There is a bit of misinformation that if you approach disability from the social model—which effectively says that much of what we can and cannot do as disabled people is not about our impairment or condition but about how society is run and organised. It is the barriers in society, whether that is the attitudinal, whether it is physical built-environment barriers, whether it is about information or working practices.

For example, disabled people have been calling and asking employers for remote working for a long time and it was viewed as impossible, but we have realised it isn't. The last two years have shown that. It is not denying that disabled people need medical intervention and support too, but this is an inclusion issue and this is about barriers in society. Society can change and we can remove barriers. That is the focus on the social model.

Q122 **Dr Ben Spencer:** The barrier, the remote working, for example, is that not the outcome of the assessment, to say that, in terms of supporting the individual, remote working is something that is helpful?

Tracey Lazard: Sorry, could you say that again?

Dr Ben Spencer: Isn't one of the outcomes of the assessment to point out that remote working would be something that would be useful for the individual?

Tracey Lazard: The assessment should be a place of gathering insights and information and it should be a resource that enables that individual and support services to understand how to support that person to address those barriers. At the moment it is experienced as a hostile, tick-box exercise that just crudely labels people. Because things like, "Are you able to work or not?" are so dependent on context and the barriers, having those fixed labels is really problematic.

Q123 **Dr Ben Spencer:** I would strongly argue that that is part of a good medical assessment. You do not see people out of context of the society, their living environment, their cultural background and so on.

One of the concerns about moving to "a more social model", is that at least with a "medical model", there are elements of that that are clearly very objective. In terms of functional abilities, particularly in physical disorders, physical exams, that is a very objective assessment and your reliability and the validity of the assessment perhaps is stronger. One of the concerns—I do not necessarily agree with this—around what you are proposing is that it is a bit more subjective.

Tracey Lazard: A social model approach—let's be clear that that needs to be co-produced and developed. It is not there yet and I don't have the



answers by any means. We think that it would combine those three elements, “What is your impairment or condition?” linked to issues like functionality, but then, “What are the personal circumstances that you are in? Do you live in a rural area? Do you have access to public transport? What is your internet access like? Are you a parent?” Then the wider barriers, which will include things like: what is the local employment market in that area? These are all factors that in the end decide whether somebody has a good chance of working or not. I think it will need to be a combination of those three elements.

Q124 Dr Ben Spencer: To unpick that a bit more—this is really helpful, and thanks for your evidence—the way I am trying to conceptualise it is that you have the more functional, objective element. You have what I would call a biopsychosocial assessment, which is what the person’s experience is, how they fit in with society and so on. Then you are saying that there is an extra part, which is where they are living, the environment that they are facing, the particular job market and what employment opportunities are available there and then. That also needs to be taken into account in terms of the assessments.

Tracey Lazard: Absolutely. If you are deciding: is somebody likely to be employed or are they likely to face exclusion from the employment market? That has to take into account all of those things. I would strongly say that we are not advocating for a biopsychosocial model, because disabled people’s organisations have huge concerns about how that has been used. However, yes, they need to take into account the real things that decide whether disabled people have a good chance of getting work or not, for example with a WCA, and that is currently not the case.

We know that the DPOs we work with are telling us that the medical evidence that they do get is ignored and they are not believed themselves, so there are fundamental problems even with the more functional medical elements of the process at the moment.

Patricia Vespuccio: I agree with everything that Tracey has said. I would only add—as Tracey has just said—that in terms of the actual processes, if you are going to come from a perspective of a social model of disability, the whole person needs to be taken into account. The attitude of the healthcare professionals and the barriers that exist at the moment in terms of the application, all of that needs to be considered.

You have heard many other witnesses saying how important it is to have all the assessments recorded and that people should be seeing their medical report. All those things would help to improve trust and transparency and remove barriers, which is what the social model of disability is about.

Jane Hunt: We all have to remember that medical doctors don’t know everything about the client. That has to be considered. How does the medical person know what the disabled person can do at home? We have to describe what we cannot do at home. That is the issue. The system



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does not accept what the person has said in the interview, and I think that they need to listen to what we say. It needs to be complemented by talking to the disabled person and assessing what they need. We all know that costs are going up and benefits aren't. I am not going to go into that, but there has to be a way of trying to accommodate the issues.

Q125 Dr Ben Spencer: Thank you, that is a very good point. I am going to avoid temptation to go into a subjective-objective debate and change tack a bit. Patricia, in terms of the work that you do supporting young people, do the needs of young people differ substantially from other groups and do they differ particularly compared to older people in terms of support assessments and going through the process?

Patricia Vespuccio: When it comes to vulnerable people, whether young or adults, their needs are very similar, but there is some extra support that young people need. I would say that, in general, the majority of our clients are vulnerable. They need a service that is very flexible and accessible to them, based on a trauma-informed approach.

For example, young people might have more difficulty in engaging with the service initially and they might need support in different ways. You have to persevere a bit more sometimes for them to engage with you. You cannot just have one of those services where if they don't answer your phone call three times or they don't turn up to appointments three times then you say that you are not supporting them anymore.

My colleagues who work with young people have said that there are two groups that we work with who are very vulnerable—care leavers and young people who are currently estranged from their families. That level has increased. I am deviating a little bit, but I want to say this, which I think is an important point. The number of young people who have become estranged from their families is growing quite significantly. Their needs are quite high because they are now estranged from their families. They do not have any support, any family, any other support network. A lot of them are living in a very precarious housing situation—sofa surfing quite often—which means that they lose their documents. They lose their ID. They don't know what their National Insurance number is. Their lives are inherently more chaotic, which then affects their mental health. They can be often in crisis and that is quite resource intensive.

Another point is that young people might need more encouragement to challenge a decision. They might not understand that that is one of their rights, so they might need some extra support there. I am just going to check my notes for a few other things that I have written in terms of what extra support they need. Yes, ID is an issue.

The other thing is just to say that casework is really important in these cases, because for young people if you are seeing the same person it is much easier if you don't have to repeat your story. We can have the consent; we can do some of the work without them being there. It takes a long time to get through a helpline and it is not easy to say to a young person, "Sit here with me for an hour until I can chase your PIP decision".



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There is all that support that is not just for young people, but it is sometimes more difficult if you do not have casework.

Q126 Dr Ben Spencer: Thank you. That is interesting. Getting me to sit for an hour to wait for someone to answer the phone would be incredibly frustrating, and I certainly do not count myself as a young person anymore. How strong is that difference in that sense between all the different people you are supporting?

Patricia Vespuccio: It is not different. You are right that it is the same if you are younger or an adult, but it might be that a young person feels a bit more impatient or might prefer to be doing something else with their time than sitting there for an hour. Yes, it is difficult for adults as well, absolutely, and our charity does casework not just for young people but for adults too, which we feel very lucky to be able to do, because it is hard to offer that support on a one-off basis. People might not engage if they are seeing a different person every time.

Dr Ben Spencer: That is really helpful.

Tracey Lazard: I totally echo Patricia's point. Access to independent advice and advocacy at every stage is absolutely vital, whether you are a young disabled person or an older disabled person. That provision is inadequate at the moment.

We have particular concerns about the vast numbers of disabled people and younger disabled people who are excluded from statutory services and support. Therefore, the likelihood that they understand what they might be entitled to and then know how to get it is quite slim. For us there is also that issue of transition into adulthood. If you are in the system and you are a younger disabled person, you might be more likely to have the support to enable you to claim. However, we are very concerned, once you get to reassessment stage, that that support would have fallen away, as much of it does when you become an adult. It is quite a cliff-edge moment. Yes, that is a big area of concern for us.

Q127 Sir Desmond Swayne: I have a question for Jane. To what extent are your managerial members accommodated and their needs addressed by the current assessment system?

Jane Hunt: Managerial positions in all areas are the same as everybody else, because they might not have somebody who is assisting them. So we support them because the forms are not accessible to them. We do support a lot of people who are professionals but not in a managerial position. They come from all walks of life. We support them in the ways that they want to be supported. We find out what they need and then get into planning what the question means. The barriers are still there. The barriers are still there. Some people cannot fill in a form by writing; an online form would help everybody. Does that answer your question?

Sir Desmond Swayne: Yes, thanks very much.

Q128 Chris Stephens: Jane, we will start with you again. I am going to ask



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some questions around support for claimants. In previous sessions we have discussed the support that people often need to complete their applications, and the best way for DWP to deliver this. What measures or programmes would you like to see put in place to help people with their applications?

Jane Hunt: You need to have an online application where you can fill it in and send it back online, or some people may want to write it or type it up on a computer and then print it out. At this time I think there is an online copy but you have to print it off. Bear in mind that the form is 38 pages long and nobody wants to print off 38 pages. Clearly, when they the forms get to Wolverhampton mailing centre they are automatically put on to a computer. Why they cannot do an online application is beyond my understanding. Also you need to bear in mind that you need to consider all the accessibility requirements of disabled people. People with a visual impairment, how are they going to fill it in? They have to rely on other people or get it onto a computer. There is too much reliance on computers I think. You have to think of digitally excluded people. There are a lot of digitally excluded people and how are they going to fill it in?

Q129 **Chris Stephens:** Thanks, Jane. You made a number of important points there. Patricia, Jane has raised a number of points there about accessibility formats and the size of the form, which is intimidating. What measures or programmes would you like to see put in place to help people to submit their applications?

Patricia Vespuccio: It is important that if any service is going to be commissioned, it needs to be independent and fully funded. It should be there, hopefully, not just for the completion of the forms but for the process than then comes after that; gathering evidence, challenging decisions, all of it. It is important when those services are being thought of, that people understand that it is quite resource intensive.

To see people to help them complete a benefit form can take a long time. It is often not something that you can do in 45 minutes. It can be traumatising for a lot of people. When you are measuring the success of a service like that, it is not about how many people you see but about how many people you meaningfully helped.

Another point is that there have been a lot of cuts already to advice services. There is not enough resource for the demand out there, and it is important to remember that local and national charities are already struggling. We believe that there is a role for both advocacy and advice. Those are two separate types of support, and both need to be considered. I cannot, as a benefit adviser, not mention that the legal way has left for the people who need support in welfare. It is something that I cannot just not say. I think it is to be independent, to be fully funded and to be accessible for people. It has to be flexible.

Q130 **Chris Stephens:** Thanks, Patricia, that is great. Tracey, a previous Committee commented on the need for claimants to get support with their applications, as the DWP had not provided forms and information in



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accessible formats, which Jane has mentioned. Has that problem largely been resolved in the organisations that you represent or is there still more work that the Department needs to do to ensure that forms and information are given in an accessible format?

Tracey Lazard: There is a lot of work that still needs to be done to make sure that the DWP meets its duties under the Equality Act, 12 years on from that Act. There have been a few improvements, but they are quite ad hoc and reactive. Some information has been provided in easy-read, for example, but overall it is patchy. Apparently there is a reasonable adjustments policy now, but you cannot get hold of it so it is rendered quite useless.

Therefore, we need the DWP to have a policy and to publicise that policy about what it will do, what adjustments it will make. It has a duty to anticipate those adjustments and to share that. It would make the process so much easier if claimants knew what they could ask for, but that is not happening.

There is also something about the culture. It is our understanding that when the DWP is taken to court about a failure to meet reasonable adjustments under the Equality Act, it tends to settle out of court and that learning is never shared. There is not that culture of, “We need to keep getting better” and that transparency about how to make the process as accessible as possible.

I absolutely echo what Patricia was saying. There needs to be maximum choice in terms of formats of assessment—face-to-face, online, phone—but also information as well. That policy of learning and transparency and being really clear about the reasonable adjustments that the DWP will do, none of that is happening in any systemic way.

Q131 **Chris Stephens:** Thanks. Jane, back to you. It has been suggested—and it is emphasised in a Green Paper—that the DWP should have an advocacy service. If the DWP were to go down the route, what factors would be important to ensure that that is successful and how important is the process of signposting to that sort of support?

Jane Hunt: It is very crucial to have support in place. It is very important to be aware of adapting the process to the person, to the individual. I do not think that one can avoid it because of their needs. If we think about where the assessments are being held in big cities or towns, because if the assessment centres are based in big cities and people cannot go to those big cities, you have to state and justify why you cannot go to the assessment centre. I do not think that they think about that. I think that they lead to barriers that could be removed if there were options available. Think about having the assessments in more local towns and video, teams, zoom, facetime etc. For example, a telephone call would be a barrier for some people, but not for others.

There is a lot more of telephone assessments because of the pandemic the country could have quite a lot more people having had these assessments. I welcome the fact that the DWP has allowed some



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telephone calls, but some assessments have been three hours. I had a client who said that she could not manage three hours so she asked for a break but they would not let her have a break. Then her partner said that she could not cope anymore, so they allowed a break after one and a half hours. Then they made another appointment.

Another issue is the availability of appointments. Sometimes they ring you and they tell you they are cancelling the appointment and give you another appointment. The hospital appointments may have already been made, so they the assessors expect you to prioritise the rescheduled appointment without any consideration for other long standing appointments.

All assessors need to read the information (PIP, DLA, ESA forms) given before the 'interview' I am afraid some do not. At the end of the assessment 'interview' the report that has been typed dictated or completed should agree the text with the client. Then the assessor should print off a copy before they end the interview for the client, or it can be recorded. I know that tribunals are allowing recordings if they are transcribed so you can record it as acceptable evidence for your own use. Many of us have mobile phones as a means of communication, and some clients covertly recording yourself. I think that all interviews should be recorded because some people have said that when they get the assessment report it is totally different to the assessment in the interview. Also, some parts of the report have been copied and pasted. I have seen myself that some parts of them are copied and pasted from another report. I think that a recording is going to be a crucial part of the process.

Q132 **Chris Stephens:** I totally agree with you, Jane, and one of my private members' Bills is that all assessments should be recorded. Thanks very much for that.

Tracey, is there anything that your organisation has given on the consultation on the Green Paper that you would want to emphasise to the Committee and say that it is something that definitely has to be done?

Tracey Lazard: Fundamentally, we need that overhaul. The fact that we have a 76% success rate at appeal shows that this is not working and the current process we would say is doing harm—it is that hostile. So there does need to be that overhaul.

Q133 **Chris Stephens:** Why do you think that the appeals are so high? Is it because of what Jane is saying about things at the original assessment not being noticed, or not put in the report, that were definitely said at the initial assessment? Is that a reason why appeals are so successful or are there other factors?

Tracey Lazard: There are a whole range of things that we need to look at. The purpose of these assessments—disabled people experience these often as gatekeeping, tick-box exercises as opposed to, "We want to understand what is going on for you". There are issues around culture and performance. The point about: if you are in work does that impact on



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your experience? The answer is yes. There is lots of informal prejudice that takes place in these assessments, with assessors going, “Oh, so you’ve got a pet, have you?” and thereby seeing that that is evidence that they do not really have a level of need. There is culture, there is the attitude of the assessors, lack of training, lack of quality assurance measures and then the process itself, which is too rigid and crude. There is a lot that needs to change.

On the other hand, we need independent information, advice and advocacy that is genuinely able to meet disabled people’s needs. For example, we need services that can go out into people’s homes. Most advice services do not have the funding to do that. We need well-funded, well-resourced, independent services and we need the DWP to fundamentally review and overhaul all of the aspects that contribute to the situation that we are in.

Chris Stephens: Thanks, Tracey. A last question, Patricia.

Chair: Briefly if you would, Chris. We are getting a bit behind.

Q134 **Chris Stephens:** Absolutely. You mentioned advice services earlier. What lessons can be learned from the approach that the Scottish Government are taking, which requires Social Security Scotland to make independent advocacy support available to anyone who requires it to engage effectively with the process?

Patricia Vespucio: It is great that the Scottish Government are doing that. What needs to happen is what I said earlier. Advice needs to be there for people right at the beginning, before you even make your claim, so that you know what you are entitled to—I will try to be brief—the right claims are made and you get support from the beginning. It needs to be flexible, that support. At the moment, we offer home visits to a lot of our clients. That is how people engage with us. A lot of our clients are so vulnerable that they would not engage with us if we were not literally driving to their homes. Obviously, through the pandemic we did not do that. We did a lot of phone appointments and conference calls became a major part of the way we worked. Am I answering your question?

Chris Stephens: Yes, you are answering the question.

Patricia Vespucio: Yes. It is advice that is independent and that is there from the beginning to the end, and it is casework. When you deal with complex benefits, you need casework because it is so hard. I worked in the citizens advice bureaux in the past. Obviously, I am fond of the work that they do, but it is very hard to pick up the work that someone else started, see the actions that have been taken and make that next appointment effective, so casework makes a massive difference. People tell us, “We wouldn’t be able to challenge this decision. We wouldn’t be able to have gone with this process if it wasn’t for the support that you give”. They would not have the strength to do it on their own.

Chris Stephens: Therefore, what happens in Scotland should happen in the rest of the UK?



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Patricia Vespuccio: Absolutely, absolutely. I could just have said that, couldn't I? Sorry.

Chris Stephens: I was just summarising, to help the Chair. We can move on.

Tracey Lazard: The policy of the Government seeking evidence is important too. The Government actually seeking out the evidence is really important because that is another huge barrier for people accessing support.

Chair: Thank you very much. Apologies, we are going to need to speed up a bit. We are getting a little bit behind.

Q135 **Steve McCabe:** I was going to say that what happens in Birmingham should happen everywhere.

Jane, the Green Paper "Shaping Future Support" suggests this idea of a severe disability group where people could avoid repeated assessments for PIP. What do you think of that as an idea?

Jane Hunt: PIP and WCA are totally different benefits and there are severely disabled people who work. I had a colleague who wanted to work because they needed the money. So, I think that there has to be recognition of the persons choice and control and respect. What Tracey was saying earlier about the social model of disability, you should not be worried about the medical part of it but focusing on the social part. So, rather than thinking about what you cannot do, with reasonable adjustment you can work from home in certain jobs. You can't just focus on limitation; it is about what they want to do not what you want them to do. That is about removing the barriers.

Q136 **Steve McCabe:** Thank you. If I pick up from where Jane is there, she picks up the point that the severe disability group would be limited by defining it as people who cannot work. That definition would result from a clinician's view of a person's ability to work. Is there a better way of defining a severe disability group? Is the principle itself quite a good idea or do you have some concerns about it? Shall I go to Tracey first?

Tracey Lazard: For us the real issue is stopping unnecessary reassessments. Where you have impairment that is not changing or a set of barriers that are not changing, that should trigger, "We don't need to keep repeatedly reassessing this person". That is all that is needed.

As Jane was saying, labels are often really unhelpful. The disabled people's rights movement and disabled people's organisations have been led by people who would have been labelled as unable to ever work, but because the right support was put in place, that was not the case. So let's stop unnecessary reassessments and let's base that on somebody's impairment rather than recreating another group of people, another label for people.

Steve McCabe: There has been a lot of agreement there. Patricia, is



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there anything you want to add to that?

Patricia Vespuccio: No, I agree 100%. What we see is lots of people being reassessed who should not be reassessed, very far from the labour market, very unwell. They might not fit into the new definition, but more good use of triage and evidence that is already there should be taken into account to avoid reassessments, or even a first assessment. There is often enough when a claim is made for a decision to be made on paper, if the evidence that is in front of the assessor and the testimony of the person in terms of the form is believed.

Q137 **Debbie Abrahams:** Good morning, everyone. Thank you for joining us. My questions are predominantly around self-assessment and self-reporting. What are your views about whether this would be helpful or not in a revised assessment process?

Patricia Vespuccio: People are the experts in their conditions. The majority of the time I would say the person is the expert and understands their condition. As I have said many times today, that needs to be duly considered. Sometimes their GPs might not know the level of impairment that they have in terms of day-to-day activities and their ability to work, so there needs to be a balance to this in terms of those types of evidence.

Sometimes we ask for patient summaries, which is all that these days people can get for free. Our clients cannot afford a letter from the doctors, and that does not necessarily have the information that is needed for the descriptors to fit into the boxes that now people have to be fitted into, so it is a bit of both.

There is also a group of people who might lack insight into their conditions, or not their health condition but how it affects them. I have had clients who will say, "I love reading. I love cooking", but it is only when you talk to their carers that you understand that there is a real need there. That evidence needs to be sought when there is evidence that the person lacks insight.

Q138 **Debbie Abrahams:** I should have said at the outset—my fault, Patricia, I do apologise—for both work capability assessment, which is the fitness for work assessment, and for personal independence payment assessments, which are about what you need as a disabled person to enable you to lead a full and active life, to address the barriers, do you think that self-assessment processes are possible?

Patricia Vespuccio: Yes, absolutely.

Tracey Lazard: I totally echo that. If we understand that we need to take a much more holistic view to capture what is going on for somebody, the individual has to be at the centre of that. A self-assessment process is a vital way of doing that. Of course, there needs to be a checking process but with a combination of prompts. Your point, Patricia, is right. Most of us are quite stoic. We get on; we get by. We do



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not talk about what we need. We just do it. It is hard to unpack that and to identify that it does take me four times as long to do something.

A self-assessment that includes access to support, advice and advocacy, but also a process that prompts and gives a chance for those open questions, "Tell us how it is in your life. What are you struggling with? What do you need?" That has to be at the heart of any holistic assessment process.

Q139 **Debbie Abrahams:** What about you, Jane, what do you think?

Jane Hunt: I think that all the information has been added already by the DWP. I agree with Tracey and Patricia that all the information that is already there should be looked at, not used to confirm that somebody has the condition. It should be already there. It should be like a CV for health, if you understand me.

Q140 **Debbie Abrahams:** Thank you. Can I start in the same order? Why do you think we are not doing self-assessments? What do you think the barriers are to doing self-assessments or the reasons behind there not being self-assessments?

Jane Hunt: By self-assessments, do you mean the fact that people are just filling in the assessment form and using that as a way or—

Debbie Abrahams: No, I meant why do you think the Government or the DWP do not use self-assessment and self-reporting? I agree with you, Tracey, that you are experts on your own conditions and so on. What do you think the issues are with it?

Tracey Lazard: Either by design or default there is a sense that this is about gatekeeping and catching people out—the whole kind of minimising fraud, when we know it is 0.03%. There is that culture in place, coupled with a very rigid set of descriptors. There is no oxygen to have that real conversation in the process. It does harm. It is a huge waste of money and we could do so much better if that culture was shifted and there was an understanding that, really, the issue is under-claiming of entitlements. That is the approach. We need to trust disabled people and have them at the centre of the process.

Q141 **Debbie Abrahams:** Trust. You also mentioned the cost of evidence as well. Jane, you had your hand up there. Would you like to add to that?

Jane Hunt: The holistic approach definitely has to take place. The whole question of you are to blame—you need to move away from that. You need to look at the person, not treat the person as if they can't do a thing.

Debbie Abrahams: I totally agree. Look at the person and not blame.

Jane Hunt: It is the principle.

Debbie Abrahams: Thank you for that. Can I very quickly—

Chair: Briefly if you would, Debbie.



Q142 **Debbie Abrahams:** We know from freedom of information requests and so on that 274 people a month were dying in 2019 within six months of being found fit for work. Tracey, given what you have said about the harmfulness of this process, I could give similar figures around PIP. We have heard evidence from the reviewers—Dr Litchfield recently—who were not provided with details around the peer reviews that they have done of the deaths of claimants. What do you feel about that as part of this process that we are undertaking now?

Tracey Lazard: I think it is symptomatic of a culture of reaction and secrecy. The fact is we are failing disabled people sometimes in the acutest way—for example, through suicide—going through processes and being found fit to work when somebody isn't. We need to throw light onto this. We need to be open and transparent about the fact that we are not getting this right, and we need to work with disabled people to get it right.

Q143 **Nigel Mills:** Is there any solution that does not involve a medical assessment, or do we just have to accept that, at least for some claimants, there will be a need to have one to be able to establish whether they are eligible or not?

Patricia Vespuccio: It is evidence, from what we said today—and you have heard many times—that the health assessments are not necessarily the best way to assess someone's functional impairment or capability for work. It is clear that there is other evidence; their own evidence and the evidence of their doctors is what would be useful in most cases. The high rate of success of the tribunals happens because that is the first time that that evidence is properly looked at.

There will be occasions when there is not enough information, and you might have to assess someone, but I think those would be fewer if all the evidence was given due weight.

Tracey Lazard: The role of medical evidence could be dramatically reduced in a holistic social model process. We know that there is often a misalignment between the medical evidence given and what is being checked, which is how one exists in your life, in the real world as opposed to what your medical condition is. It would play a far more limited role. That also requires a widening of third-party evidence and an approach that has that person's lived experience at the heart of it, so definitely a rebalancing going on there.

Q144 **Nigel Mills:** Assuming we are using assessment, what do you think about the suggestion that the assessor should be an expert in the condition of the claimant? Would that be a useful step forward or is that not possible?

Tracey Lazard: We feel very strongly that the quality, training, knowledge and information of all assessors needs to be dramatically increased. That needs to include an understanding of the barriers that disabled people from different impairment groups face, as well as the social model and the situation disabled people are in.



Particularly for those groups of disabled people that don't fit the kind of stereotypes of who is a disabled person and what their needs are—so people who are neurodivergent, people who have fluctuating conditions, non-visible impairment, people who experience mental distress—there probably does need to be some specialist assessor for those groups of people. The logistics of that could be managed because we are probably looking at five or so groups of disabled people who might need that kind of specialist input.¹

Q145 Nigel Mills: What do you mean by "specialist"? Are we talking about an assessor who focuses on those groups and therefore builds up experience, or are we talking about somebody who has had a bit more training or somebody who has had years of experience of those conditions before they start assessing? That latter one seems quite tricky to resource, doesn't it?

Tracey Lazard: It is a combination of specialist assessors that have a real understanding, have spent time with people with that impairment and understand what life is like for somebody who experiences significant mental distress, for example. They understand that. They are trained up and understand the needs and how to unpack a question or an answer; how to explain it.

It is more about understanding that lived experience in detail. Ideally, we want a DWP that then shares that learning with the wider assessors, so everybody's knowledge then increases. There is something definitely missing from the feedback loops around learning.

Q146 Nigel Mills: I see from my casework somebody who has multiple conditions; has some mental health issues plus some physical ones. How do you decide which specialist assessor takes the lead in that situation? Is that down to the claimant to try to specify what their lead condition might be? It is quite hard to have an assessor who specialises in everything, and then you are back to no specialism if you are not careful.

Tracey Lazard: Asking the claimant is probably a really good starting place, but that is where we need to make sure that all assessors have a really good understanding, which is absolutely critical. That is not detailed medical knowledge. That is understanding how life is for those groups of people who experience those types of barriers and that type of impairment. Having a good understanding of that is critical. The more complex somebody's situation is, the more complex the barriers and impairments, the more they need to be heard.

Q147 Sir Desmond Swayne: Patricia, can you explain the disincentives faced by young adults living in sheltered accommodation to take on extra work, or work at all, and what is the solution?

¹ Jane Hunt sent this addition after the session – "If the assessors do not know anything about the impairment could a detailed database be made available that they could then consult? All impairments vary in how the impairment affects the person 'functionally'."



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Patricia Vespucio: I spoke with my colleagues about that. Young people in supported accommodation are not worse off in work, but they might just be marginally better off because of the extra costs that they have in respect of travel and so on. Young people might still be developing their skills in terms of budgeting, so it might feel to them that they are not better off because they might have to start making some contributions towards their housing costs. That is where sometimes people might not understand that they are slightly better off, but for those who are able to work it is better to be in work.

The time that they spend in supported accommodation is really important for young people to develop those skills of budgeting, maintaining their tenancies so they can use those skills in the future.

Something that could help is their earnings disregard in housing benefit, which is £5 a week. If that earnings disregard were raised for young people in supported accommodation, that could be an incentive. A bit like the work allowance is recognition that some vulnerable groups or people in certain special circumstances might need that extra incentive to return to work or start work. It would be an incentive to young people in supported accommodation if that earnings disregard was increased.

Chair: That concludes the questions we wanted to raise with you. Thank you all very much. Thank you for the excellent written evidence that you all gave us earlier on in the inquiry and for the very helpful evidence you have given us this morning. Thank you for joining us.

Examination of Witnesses

Witnesses: Sarah Rawlings, Jasmine Wyeth and Catherine Hale.

[This evidence was taken by video conference]

Q148 **Chair:** Thank you all for being with us today. Can I ask each of you, as I did with the earlier panel, to start with one sentence telling us who you are, starting with Catherine Hale?

Catherine Hale: I am Catherine Hale. I am director of the Chronic Illness Inclusion Project. I am also the research leader at Astriid, an employment support charity.

Sarah Rawlings: I am Sarah Rawlings. I am executive director of research and external affairs at the MS Society.

Jasmine Wyeth: I am Jasmine Wyeth. I am a senior policy officer at Rethink Mental Illness.

Q149 **Chair:** Welcome to all of you. I will start with this question: do you think that face-to-face assessments are appropriate for people with fluctuating



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or invisible health conditions? What improvements might be needed to them, or do you think assessments ought to be based on completing paper forms, or third-party evidence or some other way of assessing other than a face-to-face meeting?

Catherine Hale: Chronic Illness Inclusion represents people with energy-limiting conditions, which is defined by DWP as impairment of stamina, breathing or fatigue. These are largely invisible conditions and often fluctuating conditions. The key problem we have found with face-to-face assessments is what is known as informal observations. Assessors are looking at the way people appear or behave and forming clinical judgments about, for example, their capability for work.

I just need to do a little detour to explain why this form of evidence is invalid and often leads to incorrect decisions. At Chronic Illness Inclusion we refer to energy impairment rather than fatigue, because there is an important difference. In a healthy person, fatigue is a subjective feeling that you might have but you are able to push through, whereas energy impairment is a disability where you start off with a very small reserve of energy and any kind of exertion—whether it is mental or physical—will deplete that reserve. After that exertion you often find yourself incapacitated or more incapacitated for a long period of time while your body is recharging that energy supply.

Going back to the face-to-face assessment, a person typically undergoing this may use up their entire energy reserve for a whole week because of the physical effort of getting there, but also the mental effort of communicating. As a result of undergoing the assessment, people are often much more incapacitated for several days afterwards; unable to leave their home, for example.

Being judged about how you appear or behave during an assessment gives a completely false impression of your capability because the assessor isn't seeing the impact of the assessment and how incapacitated people are afterwards. This is a huge problem because informal observations are leading to incorrect judgments and incorrect decisions for people.

Q150 **Chair:** Would you favour a paper-based alternative?

Catherine Hale: For people with energy-limiting conditions, it is much more appropriate to have a paper-based system whereby you have the time, the scope and the necessary support to report how your condition is affecting you from a medical or healthcare professional, or evidence from somebody who knows you best to supplement that, if that is available. A combination of those two options is usually enough for somebody with an energy-limiting condition unless there is not enough evidence on their form. Some disabled people might prefer to give evidence verbally than on paper, but we typically find that giving evidence on paper is the best way for people to report how their condition affects them.

Sarah Rawlings: For people with MS, we do think the face-to-face assessments are probably not suitable because they do not really assess



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the fluctuating and hidden nature of some of the symptoms of MS, which can be very difficult. Assessment guidance does require assessors to consider the fluctuation of symptoms, but all too often people with MS tell us that they feel that has not been taken into account during their assessment. They feel that they have been assessed on their good days, on things that they can do, rather than the bad days that they may have. For example, a person with MS may one day be able to walk to the shops but the following day may not be able to do that, or even to walk across their living room. We feel this is not always taken into account by assessors.

Assessors are also required to consider whether a claimant can do activities in a timely fashion, repeatedly and safely. However, we do know that some people with MS feel this is also not taken into account by assessors. The informal observations that Catherine has mentioned play a huge part in how that person is assessed. For example, watching a person with MS walk from the car park into the assessment centre may lead the assessor to believe that means they can walk 20 metres, without really considering those hidden symptoms or the effects they may have the day after, or in the next few hours, and that they actually cannot repeat that.

We also have real concerns about the assessment criteria being used. In particular, the 20-metre rule for assessing mobility for PIP fails to consistently or reliably record those mobility needs for people with MS. There are lots of things that we would like to see changed.

We have asked people with MS, when they have seen their full report for their PIP assessment, whether they feel that it is truly an accurate reflection of how their MS affects them, and 61% answered, no, that they felt it did not accurately reflect things such as fatigue or the hidden symptoms that they may experience on a daily basis. Therefore, we would really like to change the assessment criteria to more effectively consider the fluctuating nature of MS. That includes removing the PIP 20-metre rule and making sure we pay attention to: can somebody do an activity in a reliable timely fashion repeatedly and safely? For people with MS, we just want to add that a more paper-based approach—for many of the reasons that Catherine has outlined—would be extremely beneficial.

Jasmine Wyeth: For people with severe mental illness, neither the WCA nor the PIP assessment work for them face to face. They say that neither caters for mental illness. They both seem to be primarily focused on physical conditions; and we agree with the point about informal observation.

We have a money and mental health advice service and our advisers have told us about the really outdated views assessors have written in their reports, such as the person was “rocking back and forth”. These are just very outdated stigmatising views of mental illness, and so they are not being catered for in that sense.



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Many mental health conditions do fluctuate and aren't immediately visible, and this is a problem for many of our beneficiaries. Symptoms of poor mental health are unpredictable; they can vary from week to week. Associated with that a lot of people with mental illness have memory problems, so it is hard for them to talk about how they have been recently or predict how they might feel in the future.

Social anxiety is symptomatic of a lot of mental health conditions. Perversely, that can compel people to try to perform as being really well even though they are really not well. That makes it even harder for them to get across the severity of their condition in a face-to-face assessment.

We think that many of our beneficiaries would prefer a paper-based assessment, because that would be less anxiety-inducing than speaking to someone face-to-face. We would argue that flexibility is key because, just like anyone else in society, people with mental illness have individual needs and preferences. Ultimately, we think that more needs to be done to place emphasis on the medical evidence that is submitted so that fewer people are going through those terrible experiences in the first place.

Q151 Debbie Abrahams: You may have heard me asking the previous panel about the inaccuracies in the assessments and the implications of that around work capability assessments: 274 people a month are dying within three months of when they have been found fit for work. With PIP it is 60 people a month who die within six months of having their PIP assessment refused.

Can I ask you about the harm that you think the process is doing? There is quite a bit of evidence out there already, but what do you think the independent harm of the process is, of both the Work Capability Assessment and the PIP assessment process, with regard to the impact on both physical and mental health conditions?

Jasmine, do you want to start because I know Rethink has a current campaign for an independent inquiry into the deaths of claimants.

Jasmine Wyeth: Yes. As you know, we are currently working on a Stop Benefit Deaths campaign and harmful assessments is one aspect of that. We think many sorts of harm currently arise from the welfare system, including administrative errors made by DWP and the benefit rate simply not being enough. Assessments is a huge part of that and, because they are such traumatic experiences, they can exacerbate already poor mental health. They can trigger mental health crises—unfortunately, in some cases leading to people attempting suicide and completing suicide—and so it is a really significant harm.

For lessons to truly be learned and to lead to a substantial change in the welfare system, we would like the Government to hold a public inquiry. Ultimately, that is the only way that lessons can be learned because, even if we make small incremental changes to assessments here and there, they are going to be of limited effectiveness. We need an inquiry to understand the full extent of harm. We also want a new investigative



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body to be set up, so that future cases of harm can be properly investigated independently of DWP's existing processes, which we think are not doing enough for DWP to learn lessons from those cases.

Sarah Rawlings: From talking to people with MS, we do know that the stress and anxiety caused by these assessments is significant. As we will talk about, I am sure, there are ways we can reduce that. For example, we can make better use of paper-based assessments and follow up that evidence so that we don't have to put people through that situation.

In the previous session we talked about how people are made to feel as they go through the process. Some of the words that people with MS used to describe it to us were, "made to feel like a fraud", "a liar", "worthless", "useless", and "small". People do find these situations incredibly stressful and feel like the assessor is trying to spot inconsistencies in their story, rather than support them through a process whereby they are trying to get the support that they feel they need to manage their daily lives.

Q152 **Debbie Abrahams:** Thank you. Catherine, we have talked about the impact—not just of the assessment itself but of the process leading up to the assessment—and the stress and how that affects energy-limiting conditions.

Catherine Hale: Absolutely. Virtually everyone we have spoken to through Research has experienced a deterioration or a relapse in their physical health condition as a result of the stress of the entire process: the worry and fear leading up to it, the assessment itself and then very often the appeals process they have to go through to get the benefits that they need to live on.

Very often, people develop mental health conditions as a result of this assessment process. To start with, they may have just had a physical health condition, but they are often developing comorbid mental health conditions, depression and anxiety. As the two speakers have said, the trauma of the assessment is the experience of being disbelieved and of your testimony being twisted and framed to imply that you are lying.

We must not forget the acute financial insecurity that people are living under. They may have recently lost their job, lost their home, or they may not be able to meet their mortgage payments. These are acute moments of stress in people's lives, regardless of the assessment system, where they are struggling financially. That financial insecurity of knowing that you are going to be constantly reassessed and whether you will be able to keep your home depends on whether your assessor tells the truth or not.

All these factors combine to create huge amounts of stress and anxiety. We invariably see people's health deteriorating and they are moving further away from the labour market than they might have otherwise if the process had been supportive rather than hostile.

Q153 **Siobhan Baillie:** Thank you for joining us today. A quick question on the



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paper versus face-to-face assessments. We have heard some really powerful evidence about this, and I am pretty much persuaded that face-to-face is problematic for a lot of people. I also thank the Dursley ME group and the Down syndrome groups that have talked to me about this separately.

I have done some digging and one of the reasons the system was changed from the paper-based DLA was that it is impossible to devise a test that can be subjective enough to determine an impartial and reasonable result. It was challenging people when they were asked to complete the form; I think the DLA form was 30 pages long. Communicating conditions was problematic for some people, and a lot of the ability to challenge decisions from a paper-based system was also considered unfair. I have a little bit more sympathy with the Department and for the reasons the changes were made back in 2013.

You are obviously very clear about the face-to-face issues. Do you think the answer is giving individuals choice? Salford University has done some work on this. Is that the middle way and we make sure that there is an option for people making the application? Catherine is nodding. I will bring you in first.

Catherine Hale: Yes, I do think that is the way forward. I agree that for some disabled people reporting verbally will be a better option than reporting on paper. That option should be there if that is the best format for them. For many disabled people, especially with invisible and fluctuating conditions, once they have done their paper form, as we all have to do, there is no added value in asking them to repeat everything again in a face-to-face assessment.

Sarah Rawlings: Choice is fundamental, but I would reiterate that we have found for many people with MS that a paper-based system would be far more beneficial. MS is a progressive, lifelong condition. There is no cure for MS and it is not going to improve over time. The anxiety caused by repeat assessments, where people feel that they are having to say again and again how MS affects them in their daily life, is incredibly stressful. We could get most of that information, if it is done correctly, through a paper-based process. It requires better evidence collection from a range of different people to provide that, but it is a really important element.

Jasmine Wyeth: We would agree with everything that has just been said. The choice is really key. We do recognise that for some of our beneficiaries a face-to-face assessment might work. They might find it easier to get across their condition speaking to someone in person, or they might prefer it on the phone. We do know that for many people their situations are just so stressful they would prefer a paper-based assessment. Again, it is recognising individual needs and being responsive to those needs; being able to be flexible.

Regardless of the method of assessment, as has been said by the others, more emphasis needs to be given to the medical evidence because



people do not understand why they are asked to gather this evidence that then is apparently ignored.

Q154 Siobhan Baillie: Our previous panel said this very early on: it is pervasive through the whole system that disabled people feel they are not believed. When you start like that it becomes very difficult. They feel that evidence and documents are ignored. Whether they are or not will be up for debate. How do you think policymakers in the Department and the Government can balance those issues of wanting to make sure people feel trusted with protecting against fraud and error? What are some practical steps that we can suggest to make the situation better?

Sarah Rawlings: It is a really interesting question. A huge amount of attention is given to fraud and error within the system, and of course fraud and error have to be dealt with. That is absolutely integral. From looking at the figures, it accounts for a fraction of the overpayments, for example, and that has remained fairly static over the years.

There has to be a more positive way of tackling this as an issue, and a consideration of what is driving it. The attention that is given to fraud and error does have negative consequences on people who are claiming benefits rightfully in a legitimate way. It does create a huge lack of mutual trust and stigma around people claiming that can lead them not to claim financial support that they might need, or they are just really scared of reporting a change of circumstances because of the impact that that may have on them, even if that is temporary. If you are barely surviving on a daily basis due to living costs, it can be very scary to report a change in circumstances if you don't have that trust to know what will happen.

The DWP has done some interesting research on the messaging around fraud and error and the negative effect that it can have on people, how it can make them wary, fearful and anxious, and how moving much more to a positive approach around how you help people avoid penalties, and help them get the right support at the right time can develop a relationship of mutual trust. I think building this trust is going to be very important. We have to start from a position of belief.

Jasmine Wyeth: We would agree with what has just been said. We do recognise that there is error in the system, but we would say that errors made by DWP cause serious harm to claimants. That is one of the things that we talk about in our Stop Benefit Deaths campaign. Those errors made by DWP are costly because it fights them at appeal, but those errors are made when DWP does not trust claimants or the health professionals and fails to award the claimants the benefits that they need. We think it would be far more cost-effective and efficient for the Department to trust claimants and the health professionals. To put it another way, trusting claimants more is a key part of reducing errors; it is not in opposition to reducing errors. We also think it is very important for claimants to be able to trust the Department.



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At the moment, trust in DWP is so low because of some of the issues that we have outlined, for example, assessors being unsympathetic, people feeling that the assessments are intended to trip them up rather than support them and people being reassessed sooner than they expected to be. We think DWP needs to urgently engage in a trust-building exercise. That should be a priority for DWP. Claimants do not believe that any of these incremental changes to assessments will ultimately be in their best interests. Rebuilding trust would mean that claimants are ultimately more likely to engage and more likely to move towards work in the longer term.

Q155 Siobhan Baillie: Catherine, just some practical suggestions on building trust and protecting against fraud and error.

Catherine Hale: As everyone has said, I think the system has skewed far too much in the direction of protecting against fraud and error. We feel that we are treated as guilty until proven innocent. There is a need to recalibrate that and rebalance things, while obviously having checks and balances in place to control against fraud and error. If we compare with, say, the tax system, which relies heavily on self-assessment, the estimated rates of tax evasion and fraud are, I believe, quite a lot higher than estimates of fraud in disability benefits, yet that system does rely on trusting people to self-assess.

Perhaps we need to learn from HMRC about the mechanisms that it uses. For example, there could be spot checks. You could contact somebody's healthcare professional occasionally just to check that the testimony from the claimant matches with the diagnosis that the healthcare professional has. There could be practical ways of having these regular checks and balances in the system while starting from a position of trust in the same way that we do with the tax system.

Q156 Chair: If we were to move back towards a paper-based system, do you think the current PIP form contains enough information for the Department to make the decision? I think Siobhan made the point that DLA is 30-plus pages. Would we have to move back to a form more like that in order to do it? Catherine.

Catherine Hale: Yes, the evidence that we have heard is that the PIP in particular is very difficult and unwieldy. It might be shorter in number of pages, but the spaces provided to give an answer are tiny. Therefore, people feel very frustrated that they cannot give the evidence that they need to give in the tiny space provided by the form, and also that the wording is confusing, misleading and unhelpful. I used to be a DLA recipient, but I cannot remember how the wording of the forms compared.

Chair: We certainly need to have another look at the form.

Catherine Hale: The key with the length of the form is to give people more time to complete them. We have under three weeks and it is just not enough. I think people would not mind so much having a long form to



fill in if they had enough time to do it and did not feel stressed by these impossibly tight deadlines.

Q157 Chris Stephens: Catherine, I will start with yourself and then I will move on to Sarah. Your written evidence identified stress and anxiety around the assessment. That is, the period leading up to the assessment and then the period after it, obviously waiting on a decision, is a major problem for the people you support. How common are those problems and what could DWP and the contractors do to provide better support to claimants around that assessment period?

Catherine Hale: As I have just mentioned, a key factor is the length of time people have to complete the form, which works out at under three weeks. When you consider how difficult it is to get to see a GP or healthcare professional, and that people with energy-limiting conditions are limited cognitively and can probably only spend 15 minutes at a time on their form and usually need support from another person, I would say that nine weeks is a much more realistic timeframe to give people to complete the form, which would alleviate some of the stress of the tight deadline.

We also think communications could be a lot better, for example, reducing waiting times on the helpline, having a call-back option if the helplines are very busy, making written communications clearer and also allowing people to use email if that is their preferred form of communication. A very important thing would be having receipt of your form acknowledged by a text message. People are under so much stress worrying that their form might have got lost in the post and they will lose all their livelihood if they have missed a deadline, so just a simple text to say, "We have received your form" gives somebody that peace of mind that the process is moving forward.

As I think the previous panel mentioned, advocacy should be available for anybody who needs it. It should not be based on your diagnosis. People with energy-limiting conditions struggle hugely with cognitive fatigue and dysfunction. Having a knowledgeable person to help them fill in the forms and find the words to communicate how their condition affects them would all go a long way to alleviating the stress and the anxiety. Of course, a key factor is believing people and trusting people. That is the biggest difference, the biggest kind of change that is necessary, but, apart from that, all these other things would make a difference.

Sarah Rawlings: I agree with all that Catherine has said. To put it simply, for us, the main way that stress and anxiety can be improved is by changing the assessment process itself. That is very important. A lot of that is about starting from that point of belief, which we have all talked about: treating disabled people with dignity, empathy and respect throughout the process, acknowledging that people are experts in their condition and not making people undergo repeat assessments that are not necessary, where perhaps a light-touch review could work better.



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While changing the assessment process itself will reduce stress and anxiety and we think is absolutely fundamental, so is better support around the process, as Catherine was describing. There was an interesting discussion this morning about advocacy and advice, which is very important as well. It is very interesting to see that in the Health Transformation Programme some claimants have been assigned a case manager, who supports them through the process. It will be very interesting to see what the outcome of that is and what impact it has on people and their stress and anxiety.

Q158 **Chris Stephens:** Sarah, do assessors understand MS?

Sarah Rawlings: From talking to people with MS, no, we don't believe that many assessors do understand MS. MS is a fluctuating condition. There can be hidden symptoms and how one person may experience MS is completely different to how another person may experience it, which makes it very difficult. It is very individual for everybody.

Q159 **Chris Stephens:** Jasmine, is the DWP sufficiently aware of the profound impact that the application process and assessments can have on the health and wellbeing of clients? What more can it do to manage those effects?

Jasmine Wyeth: No, we don't think so. The people we speak to say that they do not think DWP is learning anything from their experiences. They do not think DWP follows up on their experiences. Again, for us it comes down to a matter of trust. Even if DWP did take some steps to try to improve things, without that starting point, as I have said, about believing the claimant, our beneficiaries just will not believe that DWP is going to be able to learn from the experience and will be able to make any significant changes that will really bring the fundamental reform that we want to see.

Again, we need that trust-building exercise from DWP, and that means holding an inquiry so that we can look at all of these issues and have those lessons in the public domain. I think that is the only way that DWP will be held to account to the extent that we need it to be in order to make these changes, which will be beneficial for our claimants.

Q160 **Chris Stephens:** Thanks, Jasmine. Catherine, the DWP published research last year into how PIP and ESA forms could be made less distressing for claimants to fill in. Do you have any views on those research findings and any knowledge of follow-up actions by the Department?

Catherine Hale: I'm afraid to say I do not know about those research findings. I do not know if you have them there to share with me. I was not aware of piloted changes to ESA forms, I'm afraid.

Q161 **Chris Stephens:** No, that is fine. We can send that. I am sure that the Committee will be more than happy to hear your views.

My last question is to Sarah and Jasmine. We have been told by several individuals that, despite disagreeing with the DWP's initial decision, they



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decide not to proceed to mandatory reconsideration. What causes those decisions and how serious are the consequences? Jasmine, I will start with you.

Jasmine Wyeth: Are you asking why people choose not to go to mandatory reconsideration?

Chris Stephens: Yes. What causes that and how serious are the consequences?

Jasmine Wyeth: It is very serious because, ultimately, it means people are not getting the money that they need to survive, and that has obvious financial implications for them and can exacerbate their mental health. A lot of our beneficiaries do rely solely on the benefits system to survive, so there are obvious consequences for them if they cannot do that. Mandatory reconsideration can take a long time.

We have heard from money and mental health advisers recently that it can take up to 13 weeks at present. That is a very long time to wait. Ultimately, if someone has gone through a terrible assessment in the first place, they are not going to believe that an internal DWP process is going to improve things because the DWP has already breached their trust, especially as they have already submitted their medical evidence, which appears to have been ignored. It would not be reasonable to them to suddenly think, "The DWP is going to change its mind".

Ultimately, it is when people manage to get to a tribunal that cases are often overturned. That is obviously a process that is within the court system and it is not DWP. We know that DWP spends a lot of money fighting those cases anyway. I think it is perfectly understandable why people would not go through that mandatory reconsideration process and that mandatory reconsideration process should probably be looked at as well. As I say, people just do not trust DWP at all and the DWP has unfortunately given them many reasons not to trust it at the moment.

Q162 **Chris Stephens:** Sarah, in terms of your members and the MS Society, for those who do not proceed to mandatory reconsideration, how serious are the consequences?

Sarah Rawlings: It really does shine a light on some of the real issues here, if people go through one part of the process but then do not continue because of the stress and anxiety that it is causing them. As Jasmine said, it will have quite significant consequences for people, disabled people who are often already struggling with daily living costs, who cannot meet the costs on a day-to-day basis, not being able to get the support that they need or not feeling able to go through a process because of the stress and anxiety it causes. That is very significant.

Q163 **Nigel Mills:** I remind the Committee of my previous declaration of a close family member claiming PIP, so these issues are directly relevant.

Sarah, it is not quite as straightforward for many claimants, this evidence-gathering, is it? Their GP can provide a list of what medication they are on and how often they have seen them, which may not be very



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often, and their specialist can say they have seen them once every year or 18 months, and for many people there is nobody else who can provide any evidence because, perhaps, aside from close family members or themselves, there is no easy evidence to gather because no one has any. It becomes quite hard then to have an assessment process that is anything other than just a self-assessment and then relying on it. Is that a fair summary for many of your members?

Sarah Rawlings: I think there is evidence that can be gathered from people that needs to be perhaps weighted greater within the current assessment process. We have heard about evidence from healthcare professionals. We do know that MS nurses often help people with MS through this process and often do have a very good understanding of the person.

It comes back to some of the discussions perhaps in the previous session as well, around holistic assessments, around understanding all the different elements that build up the picture of someone and their unique needs and what might be needed. That evidence-gathering process does need to be improved to ensure that we are collecting what is needed.

Q164 **Nigel Mills:** We need the people who give the evidence to give useful evidence to the process rather than a list of appointments and prescriptions, which is quite often what you see.

Sarah Rawlings: We have heard from MS nurses who are unsure about what it is that is most useful or what it is they should be providing. If we can provide better templates and guidance around that, that would help enormously.

Q165 **Nigel Mills:** It is quite hard because with some conditions you could say that the condition is so severe that we are pretty certain that everyone who has it will be entitled to one or other of these benefits, but the conditions many of you are talking about—we are not saying that everyone with MS should get a PIP, are we? Many do not need it yet or may never need it. Many people with MS can certainly work for a long time—maybe for their whole working life—so there is no easy fix of a white list of conditions or something, is there?

Sarah Rawlings: The current kind of 20-metre rule for PIP does not work for people with MS, and I am sure for a number of other people with various conditions as well. It simply does not assess people's mobility in a way that is currently helpful.

Q166 **Nigel Mills:** You are not saying everyone with MS should automatically get PIP and ESA on a kind of blanket basis?

Sarah Rawlings: There are different forms of MS. With some forms, people may feel more capable of undertaking work, for example, and other people will not. It is about how we understand those different needs at different stages of a person's life and because MS is so different for everybody.

Q167 **Nigel Mills:** Assuming we do need to keep some level of assessment,



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what are your views on trying to have more specialist assessors or allowing claimants to choose a specialist assessor?

Sarah Rawlings: We would like to see more expert assessors. At least people with some professional experience of neurological conditions would be incredibly helpful, if people could have access to that.

Q168 **Nigel Mills:** What do you mean by “professional experience”?

Sarah Rawlings: It is someone who really does understand neurological conditions and MS. That could be a whole range of different professional people, whether that is nurses or clinicians or, at the minimum, somebody who has undergone relevant training that is developed by charities, such as us, on disabled people, and what it means to have that condition. It is very difficult for assessors, if they do not have that understanding, to be able to ask the right types of questions that will elicit the type of information they need to make accurate assessments and not so heavily rely on informal assessments.

Q169 **Nigel Mills:** That is helpful because some people who I have e-mails from think that a specialist assessor would be a neurologist who is re-diagnosing them or something, but you are saying what you need is specific training for the assessor, approved specific training perhaps, but not many years’ experience as an MS nurse or a doctor or something. We don’t need to go that far to improve things?

Sarah Rawlings: It would be nice to have both. What we want is to be able to match far more people than we currently do with experts who can accurately make those assessments for them. Logistically, that seems quite challenging, but I think if we move to more paper-based systems now, we do not necessarily all have to be in the same room to make those assessments. There is online and video. There are lots of things that we can do here, I think.

Q170 **Nigel Mills:** Catherine, anything to disagree with or add to what Sarah has been saying?

Catherine Hale: It would be ideal for everyone to be assessed by somebody who has expertise in their condition. It may not be practical to find somebody with expertise in every single disease that might be presented. What we find with energy-limiting conditions is that people usually have more than one condition, which is very common with autoimmune conditions. For example, our beneficiaries tend to have at least three different diagnoses and, in about 40% of cases, a comorbid mental health condition.

What is important is for assessors to be better trained in the lived experience of different types of impairment, obviously mental health, neurodiversity, sensory impairment and energy impairment, energy-limiting conditions, and to be equipped with an understanding of what the dynamics mean in day-to-day life of having an energy-limiting condition.

We also think that occupational therapists probably, out of all the specialisms, have the best approach to understanding the functional



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impact of those mental and physical health conditions. A training approach that combines that occupational therapy approach and expertise, supplemented by lived experience expertise, is the approach that is needed to make sure that all assessors have appropriate training in different types of impairment and disability.

Q171 **Nigel Mills:** Thank you. Jasmine, anything to add?

Jasmine Wyeth: We would echo what has just been said, but we would say that the inappropriateness and lack of expertise of assessors is one of the things that we hear most from our beneficiaries when it comes to assessments. They do often explicitly say that they want to be assessed by a qualified mental health professional. That does not necessarily have to be a psychiatrist. For example, it could be a community psychiatric nurse, but this is something our beneficiaries regularly say that they want. We support Scope's campaign for an appropriate assessor and we think that people should have the right to ask for an appropriate assessor.

Catherine has just talked about comorbid conditions. Our beneficiaries say that, if they are claiming for both a physical and a mental health condition, the assessor often focuses on the physical health condition and completely ignores the mental health condition, even if the claimant thinks that the mental health condition is the primary condition. We would like to see that as something that is looked at specifically.

I want to share an example of the serious consequences that can have when the assessor is not appropriate. In our recent report, "We're just numbers to them", which is part of our Stop Benefit Deaths campaign, we included the experience of Amanda, who has experienced depression and anxiety since her teenage years. She told us, "The assessor didn't seem to listen to anything that I said. I felt like she had already decided I was making things up. I became more and more distressed and upset as I realised what she was doing, discounting everything that I said". Because of that experience, unfortunately Amanda ended up attempting to take her own life, so the consequences of having an assessor who does not have that expertise can be extremely serious.

Q172 **Nigel Mills:** As a final question, should the process really be: submit claim, submit evidence, someone looks at it and says, "That is enough, you get the benefit, move on" or, "That is not quite enough", request more evidence or then request a medical assessment, rather than what seems to be a send application form to assessor, do assessment and then look at the evidence you have afterwards, when you can sift all those that we should know from a paper base that we need the assessment?

I suppose the claimant could then choose, "Yes, I want the physical in-person assessment" or, "No, I don't and I will give up at that point". Is that a better system, to have a preliminary decision before you need the medical rather than default to almost everyone having a medical? Catherine, you are nodding at least.



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Catherine Hale: Sorry, I wasn't sure who your question was addressed to. Yes, I do think that would be the right approach, more of a triage approach. At the moment, as you say, almost everyone has a face-to-face assessment as well as the paper form that they have filled in. For people with invisible fluctuating conditions, there is no added value in having that face-to-face assessment. All it does is cause exhaustion, stress and anxiety and cost money. These assessments cost a huge amount of money.

I believe that, unless somebody prefers to give evidence verbally rather than on paper, the process should start with a paper assessment and collecting medical evidence if that is available, and if there isn't enough evidence in the form, or the person prefers to report verbally, only then should there be a face-to-face assessment.

Q173 **Nigel Mills:** Should that process be done by a DWP decision-maker or by Capita or Maximus or whoever are doing these assessments? Should it be sent to them and they decide whether to do an assessment, or should it be a DWP person who then only sends it on to the outside companies if they think there is a need for their involvement?

Catherine Hale: That is a very good question. I am not clear what training DWP decision-makers have; how much of the right kind of training they have to be able to assess paper evidence and medical evidence. I do not think we have much clarity about their training and what their approach is. It is the case that either the DWP decision-makers need much more training—for example, by occupational therapy and lived experience experts—or I guess maybe, as the system currently is, that decision would need to be done by the contractors at the first stage. I am not quite sure what the answer is.

Q174 **Steve McCabe:** I want to ask about this Severe Disability Group that is referred to in the Green Paper. Jasmine, I will start with you. If I have this right, Rethink Mental Illness believes that it is broadly a good idea because the evidence is provided by clinicians rather than any other form of assessment, but you are rather sceptical about the narrow way the criteria are drawn, in that it is people who have lifelong conditions that are unlikely to improve and who are unlikely to work. Is that a fair assessment of what Rethink feels about it?

Jasmine Wyeth: Yes, we do think there should be more recognition within the system of people who do have lifelong conditions, but who may never be able to work. We do think the positives are the proposals that the clinician could initiate the application and that the applicants would not have to go through a face-to-face assessment, but we think those principles should be extended throughout the system to all disabled claimants.

While those are positives, we do have serious concerns about the eligibility criteria, as we understand them, because as with the current criteria for PIP and WCA, they do not appear to have been devised with mental health in mind. They seem to be very much focused on physical



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health conditions and the specific impacts of severe mental illness, such as, for example, lack of motivation. Anxiety and hopelessness do not really come through in that criteria. If the Severe Disability Group was to go ahead, we want to see a redesign of that criteria to focus more on mental illness. We also think it fails to account for fluctuating and invisible conditions, as we said earlier.

We do worry that that combination of the physical health focus and the small numbers of claimants that DWP envisages will be placed in the Severe Disability Group ultimately means that, in practice, if it goes ahead, people living with mental illness will be excluded. That may be due to just cultural stigma or lack of understanding of the severity of mental illness. Yes, we do think there are a couple of positives, but they should be extended throughout the benefit system anyway.

Q175 Steve McCabe: Sarah, if I understand it, the MS Society is broadly in favour as well. You say that it mirrors the rules for terminal illness, which exist at the moment. Are there any reservations you have about this?

Sarah Rawlings: We have cautiously welcomed the introduction of the Severe Disability Group. However, I think, as with anything, the devil is going to be in the detail. There perhaps could be more transparency in the process about how the eligibility criteria are being developed and the involvement of more charities and disabled people within that as well.

One of the concerns we have is that the focus of the Green Paper has been on reducing costs and also getting people into work, including people in the support group. We are quite worried that the Severe Disability Group will eventually replace the current support group. If this happens, the main risk is that, while those in the Severe Disability Group will be relatively protected, there will be fewer of them because of the criteria.

There could also be this group who exist slightly outside of the criteria, who end up being subject to conditionality around finding work that is not appropriate for them. We have a lot of concerns, and more information would be very much appreciated to understand what this does mean for people.

Q176 Steve McCabe: How concerned are you about this aspect of the clinician determining a person's ability to work?

Sarah Rawlings: Our understanding is that the SDG will follow the process of special rules for terminal illness, which means that there is an important part for the clinician to play in that. It would be great to understand the role that the clinician will play in that and the impact that it also has on them, but also how we manage expectations, for example, if somebody wants to apply for SDG but their clinician does not think it is appropriate or they apply and it is not successful. There is quite a lot to unpack there.

Q177 Steve McCabe: Thank you. Catherine, there are people with quite complex conditions who are in work. It looks as if they would be



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completely excluded from this Severe Disability Group. Is that your understanding?

Catherine Hale: I do not think there has been enough clarity and transparency about what the criteria are for this Severe Disability Group. That is a problem. There is a feeling it has been decided by a few professionals in a closed room, and nobody is quite clear what the criteria are.

It does make sense to have a group that is assessed at least less frequently than others, on the basis that their condition is a progressive one and it is very unlikely to improve and very likely to deteriorate. Of course, it makes sense to assess those people far less frequently or not at all.

There are also other conditions where the prognosis is less clear, like ME, chronic fatigue syndrome and long Covid, where the prognosis is more uncertain, but what we do know is that with data on ME, the longer a person has had the condition, the less likelihood there is that there will be recovery or improvement. Someone with ME is very unlikely to have recovery or improvement once they have been ill for five years. I think that the duration of the illness should be another of the criteria that is looked at when deciding on the length of somebody's award and what kind of reassessment framework they should have.

I do echo Sarah's concerns about having a third group, meaning that the other two groups are somehow seen as less severe. I think that does become problematic, and we know there have been pressures to move people in the support group into more conditionality, which we strongly oppose. Obviously, being in this group should be an open discussion between someone and their healthcare professional, as well as the DWP.

It obviously does not mean that they are not allowed to or are not able to work if a suitable opportunity comes up. If you are lucky enough to find a job that you can do, say, in five hours a week, that means you are able to keep doing some work, but it should not be too rigid. Of course, it makes sense to reassess people less frequently if there is much less chance statistically of them improving or recovering.

Q178 **Chair:** Lastly, you have all called for a more holistic assessment than the one that is in place at the moment. You have suggested that people should be able to fill in a form to explain the impact on them, and perhaps evidence from specialist nurses or others might be included. Is there anything else we have not mentioned that you think this more holistic assessment might include? Catherine, if you have anything.

Catherine Hale: Yes. We have quite a lot to say about that. One of the key problems with the Work Capability Assessment is that it gives no measure of what is the key measure. For someone with an energy-limiting condition, a key measure of their kind of proximity to the labour market is how many hours a week they can work and how reliably, given the fluctuations in their condition, they can sustain those hours.



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In my work with Astriid, most of its candidates have long-term conditions and a large majority of them have what we would call energy-limiting conditions. The number of hours somebody can reliably work is the key measure of their work readiness and how ready they are to be matched with a job.

We would like to see a complete redesign of the conversation that somebody has around their capability for work that looks at daily living in the round. Being able to work relies on you being able to fulfil various other aspects of life: self-care, managing your home and any parenting responsibilities you might have. All these are a drain on energy and if somebody, simply by looking after themselves, has used up all the energy they have in that day or week, then clearly they have no energy left to even be thinking about work.

For us, a holistic assessment means looking at activities of life, including work, in relation to each other, and understanding what the impact of these other activities has on the person in order to determine whether they have any hours available to be able to work. If so, then the question would be: how many hours a week and how reliably can you sustain those hours?

This is obviously a completely different framework than the current system, which looks at rigid activities in isolation from each other. With an energy-limiting condition, you cannot talk about work until you have understood other activities in their lives, what kind of toll that takes on a person's health and energy levels and whether there is any capacity for work outside of those things.

It would be a very different kind of conversation. To come up with maybe a measure of how many hours a week you can do is a far more useful measure of somebody's proximity to the labour market than whether they can pick up a pound coin or the kind of activities measured in the current system.

Q179 **Chair:** Thank you. Sarah or Jasmine, anything else to add for what a more holistic assessment might include that we haven't already talked about?

Sarah Rawlings: I think Catherine has summarised it very well, about this need to look purely beyond the functional measures and look at the real-world barriers that people face in their daily lives and the impact it has on them. Perhaps there is a focus at the moment very much on the condition and not the individuals and the unique needs and barriers that they face.

Jasmine Wyeth: I would just say that it is about centring the claimant as the expert on their own experience. As part of that, we would want to see the Department itself engaging with experts by experience to find out what they would want from a holistic assessment.

Chair: That concludes the questions that we wanted to put to you. Thank you all very much for giving us such interesting and helpful answers; lots



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for us to think about. Thank you also for your written evidence.

If anything occurs to you after the session that you would have wanted to say to us, please do email in. We are very keen to hear further from you if you would like to contact us again. Thank you very much for being with us. That concludes our meeting.