The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

WELFARE REFORM COMMITTEE

Tuesday 18 February 2014

Session 4

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WELFARE REFORM COMMITTEE
3rd Meeting 2014, Session 4

CONVENER

*Michael McMahon (Uddingston and Bellshill) (Lab)

DEPUTY CONVENER

*Jamie Hepburn (Cumbernauld and Kilsyth) (SNP)

COMMITTEE MEMBERS

*Annabelle Ewing (Mid Scotland and Fife) (SNP)
*Linda Fabiani (East Kilbride) (SNP)
*Alex Johnstone (North East Scotland) (Con)
*Ken Macintosh (Eastwood) (Lab)
*Kevin Stewart (Aberdeen Central) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Audrey Barnett
Donald McKenzie (Support in Mind Scotland)
Rosena McKeown

CLERK TO THE COMMITTEE

Simon Watkins

LOCATION

Committee Room 3

Scottish Parliament

Welfare Reform Committee

Tuesday 18 February 2014

[The Convener *opened the meeting at 10:00*]

Decision on Taking Business in Private

The Convener (Michael McMahon): Good morning, everyone, and welcome to the third meeting in 2014 of the Welfare Reform Committee. I ask everyone to please ensure that their mobile phones and electronic devices are switched off.

Our first agenda item is to take a decision on whether to take item 3, which is consideration of specific aspects of our work programme, in private. Do members agree to do that?

Members *indicated agreement.*

Your Say—Long-term Conditions

10:00

The Convener: Agenda item 2 is a your say session that will focus on the experiences of people who have, or who are supporting individuals who have, long-term conditions and disabilities.

We have held three your say sessions to date and they have proved an invaluable way for the committee to hear from people across Scotland about their views on and their personal experiences of the new welfare system.

I welcome today’s witnesses, who are here to speak about their experiences of that system. They are Audrey Barnett; Donald McKenzie, who is a senior mental health support worker with Support in Mind Scotland; and Rosena McKeown.

I invite the witnesses to read their submissions to the committee, following which members will ask questions so that we can get a greater understanding of the issues that they have raised. I think that the witnesses have agreed the order in which they will speak and that Audrey will go first.

Audrey Barnett: I worked for the Department for Work and Pensions from 1992 until 2007, when it had become impossible for me to continue. My health had become too bad and I had to take long-term sick leave.

Early in 2008, I was given medical retirement. I claimed incapacity benefit from when I went down to half pay in December 2007. In November 2012, I received forms to change from incapacity benefit to employment support allowance. Filling in the forms was quite difficult. I know how much I struggled with the forms, even with my working background, and it must be even more horrendous for people with little experience of the benefit system. The forms are only suitable for illnesses that are straightforward and consistent. They are not designed to deal with fluctuating conditions such as multiple sclerosis or systemic lupus erythematosus, both of which I suffer from.

The forms took me a long time to fill in, especially as I had details of 12 health conditions to put in. It caused me a lot of stress trying to answer all the questions, and I felt that it was very hard for me to give a full picture of what it is like to live with my health problems, due to the nature of the questions. They concentrate on certain areas, but not all health conditions fit into their boxes. One symptom that is caused by both MS and SLE is fatigue, which is a common symptom in many auto-immune diseases, yet it is not taken into account anywhere in the claim. It is extremely disabling—you just cannot keep going when it hits you; trying just makes you more ill and the fatigue gets even worse.

Filling in the forms was exhausting as well as stressful. It is also very upsetting having to think about how badly I am affected by my health conditions. I try to be a positive person and having to focus on the negative was awful. I suffer from anxiety and completing the form made it worse.

I also suffer from benign paroxysmal positional vertigo, which is brought on when I look down. Completing the form made the dizziness come on and it took quite some time to pass. I did the form over a month to try to avoid that, but I had so much writing to do that it was still enough to set it off. As a result, I could not do much for a few weeks, my husband and mum had to do even more for me, I could not go out and I certainly could not drive. It is common knowledge that most people get put into the work-related activity group for ESA, and that knowledge made filling in the forms even more stressful. I had a fair idea that it was going to be the start of a lot of stress.

My ESA forms contained details of all my medical conditions and my eight different doctors and nurses. I explained how I had had to give up my job with the DWP and had been awarded medical retirement. I also enclosed a letter from my general practitioner that stated that I have MS and SLE, and that both are progressive, unpredictable, on-going and incurable illnesses, which I will never get better from. She stated that on-going symptoms of fatigue, anxiety, muscular aches and weakness are symptoms that make it extremely difficult for a person to have any sort of regular employment. She invited the DWP and Atos to contact her if they required any further information. They did not do so. In fact, they did not contact any of my medical professionals.

In time, I received my decision letter from the DWP, telling me that I had been put in the WRAG. Enclosed with the letter was a leaflet about what to do “If you think our decision is wrong”—what people should do if they think that their jobseekers allowance decision is wrong. I could not believe or understand it. How could I be classed as not fit for work now but be expected to be fit within a year? It made no sense, given the nature of my illnesses.

Receiving the letter brought on a full-blown anxiety attack, something that I had not had for some time—and they are horrid. I was not fit to do anything about it that day, but the next day I phoned the DWP for an explanation. I eventually got through and was told that somebody would phone me back either that afternoon or the next morning. They did not. I phoned back a few days later, and the same thing happened again.

A few days later, while I was at the MS therapy centre for treatments, somebody from the DWP phoned three times. The third message that she left was very stroppy, saying that I had asked for them to phone me back that day but had not bothered to wait in. I phoned again and managed to talk to somebody, who said that they would send me an explanation of the decision. All they sent was a single page, telling me that I had been placed in the WRAG. I arranged to visit the citizens advice bureau, and the lady there was horrified at how I had been treated. She took on my case. She suggested that we put in for a reconsideration, which I agreed to, and she took it from there. I cried with relief to have her help me. She was very reassuring, and that made me much calmer. She contacted my MS nurse and got her to write a letter, which she included in the reconsideration.

I was called into the jobcentre for a work-focused interview but, when I went in and explained my situation to the adviser, he said that he would postpone any action until the result of my reconsideration came through. I waited and waited to hear from the DWP to see whether the decision had been changed, and I never received a notification letter. In May, I sent the DWP details of the rate of my occupational pension for this year. When the DWP wrote to tell me what my ESA rate would be with the adjustment, I noticed the words

> “because you are in the support group”

on the letter. I was very relieved to read that, but I was also frustrated that I had spent so long worrying, when my mind could have been put at ease sooner.

I had worked for as long as I possibly could. I was permanently exhausted and had no life outside work. I was very depressed and cried a lot. I kept working for longer than I should have, but I did not want to be defeated. Being made to feel like a scrounger by virtually having to beg for benefits from a system that I had paid into for many years is horrid. I certainly never chose to have health problems, but given the way that Atos and the DWP deal with people now, people have to justify being ill.

I fully understand that benefit tests have to be done but, if someone gets to the stage where a chronic, progressive illness has caused them to give up their career, common sense should come into it, and that person should be put into the support group and left alone. Stress has a detrimental effect on conditions such as MS, so why put people who are never going to get better through regular reassessments?

Things for disabled people are only going to get worse when we are changed from the disability living allowance to the personal independence payment. A very high number of people are going to find themselves on less money than at present.

The Government estimates that one in six people will lose their Motability cars, so people are extremely worried. Many of the people who lose their cars will become housebound, leading to higher rates of depression and, sadly, more suicides. Other people will have their money reduced, preventing them from having treatments that they depend on and getting the help that they require. The change will also affect their entitlement to some other benefits, bus passes, blue badges and so on.

Donald McKenzie (Support in Mind Scotland): I have supported several people who suffer from severe mental health problems but who scored zero points in applying for ESA. In each case, they were supported by evidence from their GP, community psychiatric nurse and/or senior mental health support worker.

In the first case to reach the appeal stage that I was involved in, the tribunal chairman awarded the benefit on the spot, without me having to present the appeal, on the basis that the appellant was likely to self-harm if found fit to work. The tribunal chairman seemed less than happy at the number of cases being rejected. The other cases have all qualified for ESA at appeal or tribunal stage.

The impact of ESA has been devastating on the mental health of claimants, who have been stressed and often traumatised by the process. They have been made to feel like frauds for suffering poor mental health, and they have been disbelieved by the Atos staff carrying out the assessments. I believe that many medical examiners have little experience of mental health issues, do not take into account any additional evidence from other mental health professionals, and do not seek supportive evidence from GPs and so on.

Our service users are baffled and angry that they are subjected to this distressing and stressful process when they are clearly unfit to work. The process itself causes deterioration in mental health and leads to further depression and anxiety.

I have assisted five service users in applying for personal independence payments. The first was registered on 11 July 2013 and their PIP was awarded on approximately 20 December 2013, which is a delay of five months. The others were registered on 26 August, 1 October and 2 October 2013 and 20 January 2014, but none of those has yet been decided by Atos and the DWP. Such delays cause frustration and anxiety, and they suggest that the PIP decision system, which has only recently been introduced, is already in serious trouble.

I hope that that has been of assistance. Please let me know if you wish any further information on any of the cases.

The Convener: Thank you, Donald. We will get some more information when we have the chance to ask you some questions.

Rosena McKeown: I am a polio survivor and I am 54 years old. I am unfortunately now suffering the effects of post-polio syndrome—PPS—which is also referred to as the late effects of polio. The Scottish Government has released a report on the condition.

I was discharged from medical and orthopaedic care at the age of 15. Like every other survivor, I was told to get on with it and forget I ever had polio. That was not as difficult for me as it was for others, because I was “rehabilitated” and no longer used sticks or callipers.

I have been fully employed since the age of 16. I married in my 20s and worked part-time while the children were growing up.

My last employer was Glasgow City Council. Despite its efforts to assist me to stay in employment with the access to work scheme, and by changing my job description and so on, I found myself unable to sustain my job with it. The fatigue and muscle weakness had become incompatible even with my job-share position.

The chance of early retirement became available and I applied. I felt that that would be better than possibly being made redundant due to sickness absence.

I first encountered the work capability assessment in 2008 when I went to Jobcentre Plus. I was interviewed and it was explained to me what would be required, and that a letter would be sent in due course. The appointment came quite quickly and I did not suffer any apprehension about the assessment. My GP and the consultant I had been referred to agreed that it was PPS.

The doctor who I saw at the first assessment was courteous and seemed to have an understanding of the problems that were developing. His report reflected that, and he stated that I had post-polio syndrome. I have a copy of his report should the committee wish to see it. From then, I was put into the WRAG receiving ESA, to be reviewed in 12 months when my contribution had ended.

My second WCA came 18 months later. I had a little apprehension when attending that assessment, mostly because of the information from other people who were being found fit for work. I was greeted at the assessment centre by a physiotherapist. I asked her when we were seated in the room whether I should not be seeing a doctor as I had a neurological condition, but her answer was that she was allocated my case.

We had only begun the questions she was asking when she stated that she would have to stop the assessment as I was flagging up warnings with my answers and would need to see a doctor. I got very upset at that point. I had no idea what her warning flags were and she did not explain it to me. She left the room in search of a doctor who might be free. When she returned, she said that I could either wait until a doctor was free or reschedule the appointment. I told her that I honestly did not think that I would be able to return given the stress and the distress I was then in. I also stated that I did not think that I would be able to sit in the waiting area given the stress and distress that I was in.

A doctor became free within a few minutes and I was taken to another room. His first questions to me were regarding epilepsy, which is something that I have never suffered from. I had stated in my ESA50 that, when the fatigue is especially bad, it can cause problems with recall and I find myself unable to do anything.

10:15

In my opinion, the doctor made no effort to hide his annoyance at being called to see me. He was very curt to the point of rudeness and he was very dismissive of what I was telling him. He insisted that he wanted to see how I would retrieve something from the floor. That was extremely distressing as I have a splint on my right leg and a knee brace. It is very awkward for me to get up and down, but I did it. The doctor actually laughed at me when he asked what I did if I found that I could not push the hoover and I told him that I tend to pull it backwards.

After the assessment, which lasted for less than 15 minutes, I left in a very distressed state. I was informed by the DWP that I had been found fit for work. I informed it immediately that I would be appealing the decision and I requested a copy of the medical report from Atos. To say that I was shocked by what I read in the report would be an understatement. It was as if I was reading about somebody else. At the end, he had stated that I was suffering from back pain.

As soon as I was able, I reported the doctor to the General Medical Council. His report had only a cursory mention of polio and no mention of new muscle wasting, fatigue or the other symptoms that he had been informed about. I have heard no more from the GMC and can only assume that it is taking the complaint no further.

I took the decision to a tribunal and I had it overturned with the stipulation that I am not reassessed for 24 months. My condition has deteriorated markedly since then. I now have to use a walking stick as the muscles in my right thigh have wasted so much that my balance is impaired.

I was approached by my housing association in December 2012. I had a three-bedroom flat, and the housing association asked whether I would be prepared to move to a smaller property. I was agreeable to that as I was on the first floor and would have been approaching the housing association to find something on the ground floor with no stairs. Obviously, the bedroom tax was also a factor. I am in no position to pay out extra money.

My housing association has been extremely helpful. It has a benefits adviser and tries to help its tenants as much as possible. I filled out the application and kept my fingers crossed. My housing officer called in April and said that she had a property in mind but that there might be a delay of around eight weeks. Unfortunately, due to circumstances, I did not get moved until September. I had no choice but to pay the bedroom tax as, if you have any arrears, you are not offered a move.

The new tenancy is exactly what I need. The housing association has definitely done well. I could not have chosen better myself. Unfortunately, it has taken so long that my son has now left home to a property of his own. The housing association was fully aware that he would be leaving anon, and its benefits adviser has told me that I can apply to have the spare room for a carer to stay overnight, and it can be a family member. I need help with shopping, changing bedding et cetera, and of course I am unable to decorate, so my children are doing what they can at the weekends. I am in the process of doing all of this now.

I expect to be reassessed for ESA in 2015. I suspect that I will also be migrated to PIP at that time as I have an indefinite award for DLA. With all the changes that are taking place and the 20m rule that has been introduced, I cannot be certain that I will be awarded the enhanced rate that would enable me to keep my mobility car, so I could lose my independence. I failed to receive the discretionary housing payment when I applied in April as I did not fit the criteria. I will apply again, but I am not confident that I will fit the criteria now.

Given all of the above, and considering that the costs of energy, fuel and food are all rising, I feel that the future looks rather bleak.

The Convener: Thank you for giving us that personal information.

I say to all the witnesses that, if we ask questions that you do not feel comfortable answering—if you think that they are too personal or you do not want to give us the information that we are looking for—just say so. You should not feel that we are prying into your lives. We are just trying to understand the circumstances.

Rosena McKeown: I am still upset by my assessment, although it was some time ago.

The Convener: I completely understand that. If answering any of our questions would upset you again, feel free to say that you do not want to go there. You should feel under no compulsion to give us information if you feel incapable of doing so or do not want to do so. However, anything that you can tell us will be helpful. What you have told us so far has been helpful and I will open up the session to members to ask questions about that.

I will start with a couple of questions for clarification. Audrey, you explained clearly how difficult and stressful filling in the forms was for your initial assessment. Did your GP provide additional information at that point, to go along with the information that you provided?

Audrey Barnett: Yes. My GP gave me a letter—I have it with me.

The Convener: Did you feel that that letter provided relevant and helpful information or was it too cursory to assist you?

Audrey Barnett: My GP explained that, with my health problems, holding down a job would be virtually impossible. She confirmed my illnesses and invited Atos and the DWP to contact her for further information. I do not know whether they even read the letter; they took into account nothing that she said.

The Convener: It is helpful for us to know the detail that was provided, because we have been concerned that, in too many cases, the only initial information that Atos has had has come from the claimant, and GPs have provided no additional information. I wanted to have that clarified.

Audrey Barnett: I put my GP’s letter in with my application.

The Convener: We visited the decision makers centre in Bathgate and we were shown a couple of claims to give us examples of how the process is undertaken. It struck us—Annabelle Ewing might confirm this, as she spent a lot of time asking questions on the issue—that, although there was detailed information on physical aspects of claimants’ conditions, a major part of one claimant’s difficulties was depression and other mental health aspects, but only about one sentence from the assessor covered that on the form.

Donald, you said that, in the five cases that you looked at, minimal information was taken into consideration. Does that happen in all or the majority of cases?

Donald McKenzie: That varies from individual to individual. People who are suffering from mental health problems tend not to offload a lot of stuff on to forms, as they have spent several years trying to mask those problems, because of the stigma and because they are trying to survive. Unless claimants are asked whether they self-harm, whether they have tried to commit suicide and when they were last detained under mental health legislation, they will generally not give that information, because they do not want to think about that sort of thing. My experience is that, when they fill in such forms, that information does not come through.

The Convener: We were taken to an Atos assessment centre, where a mock assessment was done to show us how assessments are undertaken. Mental health was again chosen as the issue. It was clear that the doctor who did the mock assessment was very senior and understood mental health issues and that the actress who played the claimant had been briefed on mental health issues. We could see how, in some circumstances, a doctor who is on top of the issue could form a clear opinion; the assessment certainly allowed us to form a clear opinion about whether the person would be found fit for work. Is your concern that some assessments are, as a matter of routine, being carried out by physiotherapists or others not necessarily trained in mental health issues?

Donald McKenzie: Under the old income support and incapacity benefit system, part of my job as a support worker was to go along with people to assessments at York Place. However, our workload has increased to such an extent as a result of welfare reform that I no longer have the time or the resources to go along with people to assessments. As a result, I do not see them. Instead, I tend to help them to fill in their forms or to help with their appeal afterwards. I have to say that when I help people with their forms, they reveal the kind of information that allows Atos and the DWP to make a more informed decision.

However, when I used to go along to the assessments, I found that they were quite often carried out by a physiotherapist, a nurse or a retired GP who did not seem to have a great deal of insight into mental health conditions and who therefore did not ask the correct questions. Only a very experienced GP or someone with specific experience in mental health issues will be able to ask the correct questions that will result in a correct assessment. I have no reason to suppose that the situation under ESA has changed much—the assessments will still be carried out by people who do not really have experience of mental health issues.

The Convener: In your submission, Rosena, you said that the doctor who did the initial assessment was very courteous and understood your situation. When we spoke to Atos, it told us that it always tries to get the best information. However, you said that, in the second assessment, you were seen by someone who was not as trained as a doctor and who realised that they needed to get a doctor in. Am I right in saying that it was that doctor, not the one who did the initial assessment, who was the problem and that he did not seem particularly concerned—indeed, he was annoyed at being called in to carry out the assessment?

Rosena McKeown: I cannot speak for him—he was just rude. I felt that any time I told him something he was just not listening. I am pretty sure that he did not read the consultant's or GP's letter that came with the ESA50 because, if he had, he would have asked the appropriate questions. I have to say that I was a bit distressed at that point and, to be perfectly honest, no matter what he did he could not have placated me.

The Convener: You did not have to admit that.

Is it the case that the problem seems to come down to the individual and whether or not a doctor is carrying out the assessment or whether or not they are empathetic?

Rosena McKeown: Had the file been read, they would have seen that post-polio syndrome is actually a neurological condition. I should not have seen a physiotherapist. Given the questions that she was asking, it was clear that she, too, had not read the ESA50, because it says that when the fatigue sets in you just sit and vegetate in front of the television for 15 minutes. If you were to ask me for my son's phone number, I would have to go and look in the phone book. It is not a permanent condition—you just get so fatigued that you cannot do anything.

The Convener: Again, one of the issues that we have identified is that these are what might be called instantaneous assessments. They are about a person at a particular point in time, and they take no account of whether that person can do a full day's or full week's work.

Donald McKenzie: It is almost as if someone who is well enough to attend an assessment will ipso facto be found fit for work. If they are not well enough to attend, they will simply be given a new date for their assessment instead of their non-attendance being taken as evidence of their illness. That will happen two or three times and then, if they do not turn up, their benefit will be stopped, regardless of the fact that their inability to turn up is caused by their medical condition. That is not taken into account anywhere in the process.

The Convener: It has been said at the committee that it is almost a case of ,"If you're warm, you're working."

Jamie Hepburn (Cumbernauld and Kilsyth) (SNP): I have a couple of questions arising from Audrey Barnett's testimony and written submission. Audrey, you said that when you applied to change from incapacity benefit to ESA the forms were not particularly suited to your circumstances. Indeed, you said:

> "They concentrate on certain areas but not all health conditions fit into their 'boxes'."

What are the forms asking that is wrong—or, perhaps more appropriate, what are they not asking that they should be asking?

10:30

Audrey Barnett: One of the main things is that there is nowhere on the form that fatigue can be put, and fatigue is a massive problem as it is really disabling. The boxes are all about whether people can lift something or push a button and they do not take all the different criteria into account. The form can cope if someone has a straightforward illness that will be there for a while but will go away—a broken leg or that sort of thing—but if their condition fluctuates, the form does not work.

Jamie Hepburn: You mentioned fatigue. Are there other specific criteria that the DWP should ask about that would help it to come to a more rounded assessment of people's conditions?

Audrey Barnett: Yes, there probably are, but I cannot come up with them off the top of my head. The forms do not allow people to give the appropriate information about how their condition affects them, because the questions are all rigid. It is hard to explain.

Jamie Hepburn: You mention that you suffer from another condition, which I will attempt to pronounce: benign paroxysmal positional vertigo.

Audrey Barnett: Yes—BPPV.

Jamie Hepburn: That is what I should have said.

You mention that that condition is brought on when you look down, so completing the form exacerbated it. I am not sure whether another way of filling out the form would have been any better, but were you at least offered the option of completing the form in another way?

Audrey Barnett: No. After two weeks I got a letter saying, "Hurry up and get your form back," or that kind of thing.

When I have to be reassessed, I now know that I will get the CAB to do it for me. With my benefits background, I felt that I should not have to go to the CAB, because I should be able to do it, but I could not.

Jamie Hepburn: Did the letter that you were sent telling you to hurry up say that if you were having any problems with filling in the form you should contact the DWP?

Audrey Barnett: No.

Jamie Hepburn: Okay. The letter did not try to facilitate that in any way.

Audrey Barnett: No.

Jamie Hepburn: It is interesting that even when you got the good news that you had eventually been placed in the support group after previously being placed in the WRAG, the DWP did not tell you about that, apart from mentioning it in another letter some time later. The information was never communicated to you.

Audrey Barnett: That is right. I never received a letter from the DWP telling me that I had won my case and had been moved into the support group. When I read through a letter to do with how my occupational pension affected my ESA for last year, I noticed that it said:

> "because you are in the support group".

I thought, "Oh, I am in the support group—brilliant."

Jamie Hepburn: Some people might have missed that, so although they might technically have been informed by virtue of another letter, there could be people out there who never learn of the decision.

Audrey Barnett: Yes.

Jamie Hepburn: I turn to Rosena McKeown. You said that your housing association had been very helpful. You mentioned the assistance that you had received from its benefits adviser, although it took you longer than was ideal to move to a new home. We are interested in how organisations such as housing associations and local authorities can help to support people. What did the housing association do that was good? Other housing associations and institutions might be able to learn from that.

Rosena McKeown: Having a benefits adviser at the housing association is helpful, although getting an appointment is a problem as they are very busy. There really should be one or two full-time—not part-time—benefits advisers at housing associations and anywhere that people need help with forms or applications. I do not know how many pages long the application form for the new house was, but it was massive. I have problems writing, although not to the same extent as was mentioned previously. It took me three days to fill in not the housing form but the ESA form, because I have to stop. I cannot just say that everything is fine now and go and sit down—I am done for the day.

Having somebody there to go through the form with you is helpful. The adviser even offers to write it for you using your words. That is what is needed everywhere.

Jamie Hepburn: Are they quite proactive about letting tenants know about that service?

Rosena McKeown: Yes. It is the first thing that they tell people. They say, "We have a benefits officer on site." However, it would be better if there were not three officers on rotation so that people could see the same one and would not have to repeat everything.

Every housing association and every organisation that deals with people in social housing should have a benefits officer. I had to go to the citizen's advice bureau in Glasgow city centre because my local one operates on a first-come-first-served basis and I cannot stand at a door and queue. That was the only CAB that was able to offer me an appointment. These places are being shut left, right and centre, and people are just struggling, really.

Kevin Stewart (Aberdeen Central) (SNP): In your written submission, you stated quite clearly that you worked for as long as you possibly could. You also said that your employer did everything possible to ensure that you kept your job. Could you explain a little bit about the end of that situation?

Rosena McKeown: With my employer?

Kevin Stewart: Yes.

Rosena McKeown: They did the best they could. I could not take minutes because I could never tell how long a meeting was going to last. I worked in admin in social work and I could not really cover reception because I would have been up and down all the time and would have had to walk.

My employer was really understanding when I told them that I could not sustain it. I was working for two and a half days a week and sleeping for one and a half days afterwards. It is not right. It is not a life.

Kevin Stewart: So you did everything that you possibly could to maintain that job, and your employer did too.

Rosena McKeown: I feel that if I had stopped a bit sooner, it might have helped. I kind of came to a dead stop when I just could not do it. I never had a problem with Glasgow City Council; they were fine. They gave me chairs and footrests—anything that I needed, I got. I never had a problem until I stopped work and then I got things thrown at me that I had never heard of.

Kevin Stewart: Obviously, while you were working, you thought that you had paid into the system just in case anything happened. You thought that that safety net was there. What do you think about the situation now, having paid into a system and finding that it is not there for you at the moment?

Rosena McKeown: Angry. The DWP was quite happy to go along with the diagnosis until my contributions ran out and then, all of a sudden, it said, “OK, we’ll get this one back to work now.” It feels like that was the attitude. Having never been in the benefits system, I did not understand it and I thought that if my contributions only lasted 12 months, well, they only lasted 12 months. My first assessment stated that I have PPS, and that has not gone away. If they have found a cure, I would like to hear about it. It is not going anywhere. That diagnosis then disappears, and I am found to be fit for work. That is two polar opposites. Either the PPS is there or it is not there; it cannot be there then disappear. That is why I get angry.

Kevin Stewart: That is understandable.

Audrey, you are in a similar position, in that you worked for as long as you possibly could; ironically enough you worked for the DWP and the people you are now battling with. Do you think that you did everything that you could to stay in work for as long as you possibly could?

Audrey Barnett: Yes. I tried everything that I could. I reduced my hours. I tried to explain to the employer what my needs were and, the majority of the time, the jobs were suitable for me. However, I was just permanently exhausted and in pain. I started in the office in 1992 as an administrative assistant and I went up to the level of admin officer for a while. However, when I got diagnosed with MS, I asked to go back down to an admin assistant, as I felt that I required a job with less stress. I was then given a temporary promotion. For most of my career, I was on a temporary promotion. I did not go for a permanent promotion, because I wanted to be able to step back down if I needed to. I was really struggling. I was permanently exhausted. I had no life outside of the office. I would wake up in the morning in tears. I would arrive at the office exhausted and in tears and would try to do a day’s work. When I came home from work, I would just have to lie down. I had no life at all.

Things changed in the office. We became a social fund centre, and I went back down to my substantive grade of admin assistant. However, all the jobs were physical and, by this time, I was having a lot of joint pain. However, I had not had a diagnosis of the joint pain, so my work was not really listening to me. I felt that my only option was to go for a permanent promotion so that I was away from repetitive jobs such as filing. I got that promotion and got put in a social fund telephone section, which was way too much for me—I had to deal with constant phone calls, with minimal training. I spoke to management and the union and was taken off the phone section for about a week, when the manager was not there. When the manager came back, the following week, I found myself back in the phone section. I kept telling them that it was too much for me, but they did not care. I ended up having an MS relapse.

During that time, I was also having investigations into the joint pain. When I went to the GP with my MS relapse, I was told, “Oh, we’ve now discovered that you have lupus as well.” At that point, I realised that I just could not keep doing what I was doing.

Kevin Stewart: As I said to Rosena McKeown, given that you paid tax and national insurance, what do you feel about the fact that that safety net is being taken away from folks who paid into the system with the expectation that, if anything happened to them, they would be looked after?

Audrey Barnett: I feel really let down. It is just not fair. I have spent years on the other side, working for the DWP and, now that I need it, I am having to fight for everything. I feel that it is treating me like a scrounger. I promise I did not choose to have all these health conditions, but I feel like it thinks that I did. It is a mad situation.

Kevin Stewart: I and most of my colleagues around the table and in Parliament are getting a huge number of folk coming to us who are in major difficulties, many of whom have mental health problems. Like Audrey and Rosena, a lot of these folks have worked for as long as they possibly could before illness struck. Do you find that a lot of the cases that you are dealing with involve people who have held down jobs for too long, in a way that has exacerbated their illness, because they felt that that is what they should do?

Donald McKenzie: With regard to the people with whom I work, I would say that it is about 50:50. There are people with long-term conditions who have never worked and never will work. They might have mental health issues as well as learning difficulties, so they are already in the non-working population. However, as the employment situation tightens, other people find that they are being cast adrift by some of the big employers who are looking to get rid of some of what might be described as their dead wood. Perhaps, one day, those people were following the media’s representation of these dole-queue scrounging, “Benefits Street” layabouts, and the next day they suddenly find that they are being treated in exactly that way. That in itself is devastating. Regardless of the diagnosis or the initial problem that you have, the stigma of losing your job and getting thrown into the system causes huge problems.

I do not know whether any follow-up is done, but I know that there have been several deaths where people have committed suicide or just given up and overdosed, maybe not deliberately but just in trying to escape the stigma and the hardship that they are experiencing. I would love to know whether anyone is following that up to see how many people have died specifically following their experience of the benefits system. I think that the number must be substantial.

10:45

Kevin Stewart: Both you and Audrey Barnett have mentioned the word "scroungers". I would never use that word, but it is used quite often by a number of politicians and by the mainstream media. What do you think of the attitude that seems to be agin the welfare state that provided the safety net that we all hoped we would not need, but which was there in case we did?

Donald McKenzie: It is appalling. The most recent furore surrounds "Benefits Street" on Channel 4. I have not watched it. I watched the first episode for 10 minutes and switched it off.

Kevin Stewart: I have to say that I could not watch it.

Donald McKenzie: There are hundreds of people on the street, but the programme focuses on three or four of the worst examples and they are taken by the media and many politicians as being the standard, as if that is the way that things are in the benefits system. Nothing could be further from the truth. I find it appalling that people who are meant to represent the electorate or the population allow or actually encourage the media to go down that road.

Both Labour and the Tories now use the hard-working families idea, and everybody else is irrelevant. You do not count unless you are part of a hard-working family. If you are not working or not in a family, that is it. You are on the scrap heap.

Kevin Stewart: Thank you for your evidence, folks. Convener, we have heard today from two folks who were obviously hard working, who worked until the last minute that they possibly could.

Ken Macintosh (Eastwood) (Lab): I, too, thank you for your powerful and persuasive evidence. I have a question for Audrey Barnett and Rosena McKeown. The process that you described was clearly stressful and difficult but, at the end of it, have you lost out financially? Are you worse off than you were at the beginning? Have your benefit payments dropped?

Audrey Barnett: No.

Ken Macintosh: So, in the end, you have held on. It has been a fight, but you have held on to your benefits.

Audrey Barnett: I have held on to them so far, but I have no confidence for the future.

Ken Macintosh: Because you will be reviewed again in a few months?

Audrey Barnett: I have never had a decision letter. At some point within the next year, I will be reviewed. I just have no confidence. I am absolutely dreading it. I know that it will set the anxiety off again.

Ken Macintosh: Indeed. Rosena, do you want to comment?

Rosena McKeown: I went from working to the benefit and I just trimmed things down.

Ken Macintosh: Have the benefits reduced over the period?

Rosena McKeown: From the time when they found me fit for work until the tribunal, I was on the assessment rate, so there was a drop. They gave me the money back, but that did not help me at the time.

Ken Macintosh: I am trying to work out what happened with the bedroom tax that you paid.

Rosena McKeown: It was a family home and two of them left, so it was just me and my son, which was fine. I knew about the bedroom tax, but my priority at the time was not falling down the stairs when I went out. Just before the previous Christmas, I thought, "I'm going to have to apply and see what they've got on the ground floor", but that did not happen until the January. There was a time delay as it was an old gent who was in the house, and when he died it took a lot of time for the family to sort out the house. In the meantime, I was paying the bedroom tax, but my son was there. He is not going to let me starve or suffer from whatever needs to be cut back on.

I was worried about what would happen when the time came for him to leave. I am on the middle rate of care for the DLA, which is fine, and I have now been told that I can have the room. With the PIP rules change, however, whenever that happens, I am not at all confident that I will have it.

Ken Macintosh: You would be forced to move again.

Rosena McKeown: It will affect me then. It is like a perfect storm forming.

Ken Macintosh: You applied for a discretionary housing payment, which was refused.

Rosena McKeown: Yes.

Ken Macintosh: Do you know why it was refused?

Rosena McKeown: I did not ask. I am a bit like that. If someone says no, I tend to think, “Right, fair enough.” I assume that it was because my son was in the house.

Ken Macintosh: Have you thought about appealing that decision?

Rosena McKeown: The benefits girl spoke about what would happen if it came back. She wrote to me again and I phoned her. I told her that I was just going to leave it. I had to focus on the moving part: I had a three-bedroom house that was going to have to get squished to two bedrooms. You have no idea—I was packing for about six months, because I can only do so much before having to go for a lie-down. Other things overtook it, so I did not appeal. It is quite possible that I would have got it, but I never pursued it.

Ken Macintosh: Is it the CAB that has been advising you throughout?

Rosena McKeown: The CAB has been absolutely fantastic. I have never had a problem before. Nobody has let me down—the benefits adviser or the CAB. When I first went, I explained everything to the person there, and she helped me with the form. She was a volunteer, and she was not fully trained, and she had to pass my case on to somebody else, which I said was fine.

In between two appointments that I had, the woman I had seen spoke to a retired GP friend of hers. He explained things to her, and told her how serious the condition is and would get in the future and she told the benefits adviser who was to come to the appeal. Unfortunately, the adviser got double-booked that day. That was one let-down. The adviser was not at the tribunal, but the initial woman came, for support. She could not say anything, but she was there to let me know that it had not been deliberate or anything—it was just a bad coincidence.

Ken Macintosh: Even with that support, it was still extremely stressful.

Rosena McKeown: I have never experienced anything like it. Over the past few years—since 2006—I have not had a lot of control over stress. Once stress sets in, it keeps going and going. It will top, and that is me: everything is gone. The fatigue and the pain set in and I just curl into the pain. That can take two days. It was two days before I could even complain about the doctor, as strongly as I felt about it at the time. I physically could not get up. I typed the letter—I did not write it. I could not even do that.

“Devastating” does not cover it. I wish there was another word. It is ridiculous that anybody with a long-term condition should go through that. I did not even consider that I had such a condition—I had been told to forget about it, and I did—but it is coming back to me now, 40 years down the line. I am having to deal with bits of me suddenly deciding that they do not want to work any more. While I am dealing with that, I have to justify myself to a doctor who is not listening. It is very hard.

Ken Macintosh: I have a question for Donald McKenzie. Are the cases that you have been taking to appeal new cases, or are they all existing ones?

Donald McKenzie: It is 50:50. It is a mixture of people who have been on long-term income support and incapacity benefit and, more recently, people coming out of work or becoming too ill to work.

I have recently discovered that employers are asking people to resign, rather than sack them. I do not know why that is. Perhaps it is because they feel that they cannot sack people with medical problems or give them medical retirements. They tell their staff that they are not well enough to work, their sick pay will be stopped and that it would be better if they resigned. Of course, somebody who resigns cannot get jobseekers allowance. ESA is almost becoming a default situation for people who might otherwise have been assisted into employment. There is a mix of people with long-term conditions and people who are coming out of work and going on to benefits.

Ken Macintosh: You talked about experiencing delays with these appeals. Are people with existing claims likely to be dealt with more timeously than those with new claims?

Donald McKenzie: The delays that I talk about in my evidence relate largely to personal independence payments. Everybody on PIP that I have represented has had huge delays; only one of those appeals has come to a decision.

On ESA, I am not sure whether there is a big difference between people who have been on ESA or benefits for a while, and people who go on to benefits from having been in work. I do not really know whether there is a delay there.

Linda Fabiani (East Kilbride) (SNP): Most of the issues that I was going to ask about have been covered. Just for clarification, though, Rosena, when you saw the doctor who did not listen to you, and you received that ridiculous letter that talked about back pain and so on, you said that you complained to the GMC, once you felt able to. Did you get back in touch with the assessment centre or anything?

Rosena McKeown: I did not.

Linda Fabiani: You just moved on from that. That is perfectly understandable.

That takes me on to Audrey Barnett. You are now in the support group but you are worried about what will happen if you have to be reassessed.

Audrey Barnett: Yes.

Linda Fabiani: It is an issue about long-term conditions. Donald McKenzie talked about people with learning difficulties and people who have never worked who are having to go through this as well. As MSPs, we all see folk like that. There are some adults with learning difficulties in my constituency who I deal with regularly who are hugely distressed at the idea of their money being stopped. Donald McKenzie might be best placed to answer this question. As a professional, do you pick up any acknowledgement that this awful system is still fairly new and that there are long-term conditions that will not be sorted overnight? Is any account being taken of the fact that there are people who have perhaps never worked, for very valid reasons? Is any of that being taken on board so that discretion will potentially be used further down the line or so that there might be changes to the system?

Donald McKenzie: I do not think so. I work with a lot of people who have bipolar affective disorder, which used to be manic depression. Other people have paranoid schizophrenia. A lot of them have had those conditions for 25 or 30 years and they are now having to be assessed every year or two—sometimes it has to be every two years because the system cannot cope with annual assessments.

I had one case in which somebody had gone to tribunal and won it. They were awarded ESA for a year but, because it was a year from the initial assessment date, the year was up one month after the tribunal. They had only just got their back money and they were sent a new questionnaire. That person went ballistic. They were so distressed, angry and upset that I was surprised that they did not go straight round to York Place and kick the windows in. I was upset, too. We had just gone through all that stuff at the tribunal and they had been awarded ESA, and then a month later they get the forms to start all over again. You can imagine the despair and anger that that person went through.

It is particularly appalling for ladies such as Rosena McKeown and Audrey Barnett, who have long-term conditions and are expected to jump through hoops every year. I think Rosena mentioned that it was every two years. What is going to happen in two years? It is a ludicrous waste of medical and administrative resources to put them through this every couple of years, when there is obviously no prospect of recovery.

Linda Fabiani: Donald McKenzie is talking about resources. It strikes me that even if you get your head round the idea that those in charge do not care about the individuals, and that they want, in their words, to cut the cost of welfare, they are in a perpetual cycle in which those costs are not being cut. If there was more discretion, and if a bit more humanity was shown in these things, a better system might be achieved, resulting in cuts to costs in the long term.

11:00

Donald McKenzie: I am not sure where it all started. Perhaps it is simply that Governments have long not trusted benefits claimants, so the medical profession is not trusted to make judgments on whether someone can or cannot work. The matter is sent to the DWP, which employs people to administer and make an assessment. However, they are not trusted to make the decision, so Atos is brought in, which then employs people to administer and make an assessment. However, those people do not make the decision; they send it back to the DWP, which then makes a decision that cannot be challenged directly, because Atos carried out the assessment that led to the decision.

The GPs, specialists and many other medical professionals who are involved in the care of the two ladies on the panel and the people whom I work with are perfectly legitimately qualified to make a decision on whether someone is fit to work. When we have those professionals, I do not understand why we have to spend millions and millions of pounds going through that other process.

Linda Fabiani: We have heard from Rosena McKeown about a tribunal in which the original decision in her case was overturned. We hear that over and over again. Mr McKenzie, do you get any feedback or feeling that that is being taken on board and that changes might be made?

Donald McKenzie: Not really, because I do not get any further than the gatekeepers in the DWP and Atos. In the first ESA case that I attended at a tribunal, the tribunal chairman was dispirited by the number of cases that he was having to look at and which from his perspective appeared to be no brainers. He spoke to me outside the tribunal and said, “Listen, is this person going to self harm?” I said, “They are already self harming,” so he said, “Right, we will grant the appeal and we will not bother going through the tribunal process.” That particular chairman seemed to be trying to short-circuit the process and move the cases through because there were so many of them. So, at that external and independent level, people might be recognising that the system is not working but, within the system itself, we do not find out whether that is happening.

Linda Fabiani: Ms Barnett, do you want to say something? You look like you are raring to go.

Audrey Barnett: At the end of last year, I had a meeting with Danny Alexander, the MP for my area, in relation to a variety of things that affect people with MS, one of which is obviously benefits. He contacted Iain Duncan Smith, who sent me a six-page letter that waffled on. From that letter, it looks as though there is no intention to change anything. In it, he is justifying what he is doing. For example, he says that, with people who have illnesses such as MS, the Government has to regularly review the situation because new treatments come along. Well, if there is a new treatment that will cure me, can I have it, please? The same applies to Rosena McKeown—there is no treatment for her. However, that is how he justifies it. Basically, Iain Duncan Smith says that the process will continue and we will be reviewed. There is no sign of change.

Donald McKenzie: I have contributed to four separate research projects: the initial one by Professor Harrington about the ESA; one that was carried out by the University of Stirling; and two individual PhD projects, which I think were at the University of Edinburgh and the University of Glasgow. They all involved people looking at the benefits system and how it works.

I have noticed that the ESA form has been tinkered with over the years—the wording changes slightly and the pages are slightly different. I have reached the stage at which, when there is a review, I just dig out a copy of the previous form, fill it in for the person and say, “Sign there,” because that is the form that got them the award. I do that so that people do not have to go through the draining process of answering all the questions again. I say, “Are you feeling better or worse than last year?” and they say, “Much the same,” so I just copy exactly what I wrote the last time and change the date, then the person signs it and I send it off. In doing that, I have noticed that some of the wording and expressions on the form are slightly different, but not different enough to make a substantial difference to the process.

Linda Fabiani: It is just tinkering at the edges.

Donald McKenzie: Yes.

Linda Fabiani: I suspect that Audrey Barnett and Rosena McKeown would both far rather be well and working, and that the same is true for most of Mr McKenzie’s clients.

Rosena McKeown: Yes.

Donald McKenzie: Most of my clients would be delighted to work, but they are prevented from doing so because, if they carry out any sort of work at all, whether it is volunteering or whatever, they will have to ask their GP to say that it is permitted work, and that causes a problem.

Linda Fabiani: That is interesting.

Donald McKenzie: Someone who wants to volunteer at, say, a charity shop might think that, if the DWP discovers that they are working there, it will find them fit to work. That is not necessarily the case, but everyone is aware of cases in which people were dobbed in by their neighbours for having been seen to go to work when they were in receipt of benefits.

To be stigmatised as benefit scroungers who are working on the side impacts on people who are genuinely trying to do something, even if that is just working in the corner charity shop. Indeed, they are dissuaded from doing so because the system says that you can do only permitted work that is notified to the DWP and signed off by your GP and that sort of thing. The system works against people returning to work.

Annabelle Ewing (Mid Scotland and Fife) (SNP): Good morning to you all. I thank you very much for coming along. I hope that after this experience it will not feel as bad as going to the dentist—I hope that we are not that intimidating.

Many of the general points have been well aired, but I have a few matters that I will pick up with Rosena McKeown. You—understandably—reported the Atos doctor to the General Medical Council, but you have heard nothing further. Was your complaint acknowledged?

Rosena McKeown: Yes—that came through, but there is a parallel complaints process. On the first process, I was told that there would be no further action; on the second process, I was told that I would only hear back if the GMC was taking further action. I read the silence to mean that the complaint had got to a certain point but would go no further. However, the GMC said that the complaint would be on record, although I do not know whether that refers to its records or the doctor’s records.

Annabelle Ewing: Did the GMC communicate with you to clarify what it had done and why or was there just a silence and, from that, you were to infer that—

Rosena McKeown: No, it was pretty—

Annabelle Ewing: Opaque.

Rosena McKeown: The GMC set out what it does with complaints. It mentioned what the first process is and what would happen if Atos did not take action. As I said, I was told that the matter would be on the record, although it was not mentioned whose record that would go on. The second process was that, if the GMC thought that there was any justification in going forward with the complaint, it would contact me again. I was given forms for victim support. The GMC was really quite helpful in that regard—I just did not find out anything about my complaint from it. However, I did not pursue the matter.

Annabelle Ewing: Okay. It would have perhaps been helpful and a more useful experience for you had the GMC said—no matter what forms it sent you relating to other matters—what decision it had taken and why it had taken that decision, especially given your fairly horrible experience with a doctor who is, I presume, still registered to practice even though he laughed at you. That behaviour does not seem to be very much in keeping with the Hippocratic oath, apart from anything else.

On the appeal that you took to the tribunal, will you clarify whether any additional evidence was made available at the tribunal or was your case based on all the information that had been presented previously?

Rosena McKeown: Before we got to the tribunal stage, I sent Atos a thick file with all the information in support of my ESA claim, including letters from my GP and the consultants, as well as the Scottish Government's report on PPS. The only additional information that I put in was a printed out version of the national health service in England's map of medicine—that was the only thing that I could find that I had not included.

Annabelle Ewing: What is that document?

Rosena McKeown: We are here complaining about tick-box exercises; that is what the map of medicine is. It is a map where you can search for conditions, such as post-polio syndrome. A search takes you to information on whether your condition is diagnosed or undiagnosed. You can click on boxes that tell you about the symptoms, preferable treatment and things such as that. We do not have a similar map in Scotland. You could also google the condition to find out about it.

Annabelle Ewing: The hard medical information from the medical practitioners had already been supplied. I guess the feeling is that, had that even been read at stage 1 of the process, perhaps stage 2 would not have been necessary.

Rosena McKeown: The information was read for the tribunal because I could see those wee strip post-it notes on different parts of the evidence.

Annabelle Ewing: You misunderstand. I am saying that the fact that you had to go to tribunal to appeal seems to be not unrelated to the fact that the medical evidence that was available at the outset was not assimilated properly by those concerned.

Rosena McKeown: The tribunal also managed not to find my doctor but another consultant who specialises in PPS, even though the DWP is apparently unable to find such a specialist.

Annabelle Ewing: That clarification has been helpful. Thank you, Rosena.

I note that Audrey Barnett said that she fully recognises that benefit tests require to be done, but she feels that common sense should prevail with chronic progressive illnesses in particular. If we were to take common sense as a key factor in the whole process, what do you hope that that would result in? Common sense seems to be lacking across the board. What would that encapsulate?

Audrey Barnett: Basically, if a person has a permanent chronic and progressive condition that will simply not get any better, and has reached the stage at which they can no longer work, it is common sense to me that they will not work again. We should be put in a support group and just left alone. We do not need all the extra stress and anxiety; we have enough to cope with.

Annabelle Ewing: You mentioned that you did not receive a specific decision letter on the apparent movement from WRAG to the support group, but one might think that it would be useful to get that from the DWP in order to be ready for the next stage because it may be useful further down the line.

Audrey Barnett: Yes. I thought about that, but it is just the thought of contacting the DWP. I thought, "Oh, no."

Annabelle Ewing: Perhaps you can write now on the basis that you might get a reply within six months, if you are doing well and the DWP is true to form. You never know.

I turn to Donald McKenzie. On mental health, the convener alluded to the fact that, at the outset, we had a detailed meeting with assessors for the DWP in Bathgate, which was very helpful. However, one issue that arose was that attention to mental health issues in the very long assessment form is almost negligible. Indeed, I recall a question that was supposed to deal with mental health issues which basically said, "By the demeanour of the individual applicant, can you make the following judgment?" I thought that that was rather bizarre in the 21st century, with medical knowledge being what it is. I would have thought that deciding whether a person has a mental health problem by looking at them is a rather medieval approach.

You mentioned that you have had helpful discussions even before the tribunal process started. In cases that have gone to tribunals and in which Atos's initial negative decision has been overturned, to what extent has there been an exploration of evidence on mental health?

Donald McKenzie: Did you say "exploration" or "explanation"?

Annabelle Ewing: I mean an exploration by the tribunal. How does that all pan out if a tribunal takes place and there is an appeal against Atos's initial negative decision on mental health grounds? How does that work to the point at which there is sufficient information that results in the tribunal overturning Atos's initial decision?

Donald McKenzie: Prior to the tribunals that I have attended, I have tended to get letters from a GP, a specialist and a CPN. I then write as a senior mental health support worker. All those letters confirm that the person is unable to work.

None of the tribunals that I have been to has lasted for more than 10 minutes. One was over before it started; the others have tended to last for 10 minutes because I have collected evidence and given it. I do not know what they do then, but there has certainly not been any doubt about the initial decision being wrong in any of the tribunals that I have attended. The decisions have been overturned very quickly. Unfortunately, that has mostly been because of self-harm or people having attempted suicide in the past. If that is not explicitly mentioned in the original ESA50 form, it will not be taken into account. The tribunal chairpeople are now more geared up for that, and I think that, if there is the slightest element of self-harm or attempted suicide in a case, they tend to say that the claim is granted under rule 22.2b or whatever. I do not know what more the tribunal does. I have been very lucky; I have won all the cases very simply and easily.

11:15

Annabelle Ewing: Okay. That is helpful.

As far as the initial application stage is concerned, to what extent have you been involved in helping applicants with having the necessary information available at the outset? Is that happening more often now, given that we know that the Atos assessment form is not at all geared up to dealing with mental health issues?

Donald McKenzie: I am now working with people who filled in the ESA form a couple of years ago when ESA first came in. It is much simpler to deal with people who have been using our service for two or three years, because I know where we are at. I tell people not to fill in any forms on their own but to come to me for help.

I also see people who come to our service only because they have gone through the process and have been given zero points. I sit down with them, go through the form and explain the points system. With people who are making a claim for the first time, before we fill in the form, I photocopy the points system, give it to them and tell them to go away and spend a couple of days looking at it to see whether they think that they fit into any of the categories. I also tell them that they have to get 15 points. Then I go through the form with them and ask them whether they experience this or that.

It used to be extremely difficult to speak to people about whether they had attempted self-harm or suicide, or had been arrested or detained under the mental health legislation over the previous year or so. I used to find it extremely difficult to ask questions about those issues, but now it has become routine. People have become blasé about it, which, as a mental health support worker, I do not like. My job should be about helping people to feel better about themselves in order to improve their mental health, but in reality most of my work is on benefits, in which I have to talk people down and dig into the dark corners to get information. A person who has made a recent suicide attempt will get 15 points and will get their ESA.

Annabelle Ewing: You mentioned that you had already inputted into various reports and inquiries. Did that input include the suggestion that more specific questions that are geared towards people's mental health history should be included on the original form?

Donald McKenzie: I do not think that I have made that suggestion, because I am not comfortable with the whole process and I do not want people to have to go through it. I want the DWP to look at the information that is supplied by the people who provide professional care for the claimants—the doctors, the specialists and the CPNs. They are the people who are most able to make correct decisions on behalf of benefits claimants—not assessors and DWP decision makers who have nothing in front of them except what is written down on forms that may or may not reflect reality. The people who see the claimants regularly should make the decisions.

Annabelle Ewing: As far as the general process is concerned, do you think that it is appropriate for someone with no background in mental health to make the initial assessment?

Donald McKenzie: No. People who have no mental health background should not make the initial assessments, especially if they are being paid on the basis of results. As I understand it, the more people who get kicked off benefits, the more money Atos gets, but maybe I am just cynical.

Annabelle Ewing: I would like to ask one last general question, which is for all three witnesses. It is entirely up to you whether you wish to answer. I note that in a recent speech, according to a report on 23 January, Iain Duncan Smith, who is the United Kingdom Secretary of State for Work and Pensions,

> "compared his welfare reforms to the struggle to end slavery."

Apparently, he said that changes to the benefits system were part of

> "a 'historic mission' to help people 'break free' like William Wilberforce's campaign to end the slave trade".

Do you wish to comment on what he said?

The Convener: The witnesses should remember that this is all on the record. [*Laughter*.]

Donald McKenzie: I think that the fact that the Government was recently taken to court over its welfare reforms encouraging slavery by forcing people who are on benefits to work for private companies for nothing says it all. I understand that Iain Duncan Smith gets paid £1 million a year out of the public purse for his wife's farm—I think that that is correct. He is the biggest benefits recipient in the country. I am sorry—I am getting more and more angry.

Annabelle Ewing: Donald has set the scene, but Audrey or Rosena might have some comments that are of a different nature or in a different vein. Iain Duncan Smith says that he is setting people such as you free. Do you feel free?

Audrey Barnett: It would be nice if our health would let us be set free, but that is not going to happen. As I said, I would love for my illness to be cured, so I could have my life back and not depend on benefits, but until my health sets me free Iain Duncan Smith certainly cannot.

Rosena McKeown: What I want to say is unprintable.

Annabelle Ewing: Okay. Thank you very much, all of you, for coming along. It has been very useful for us.

The Convener: It has indeed. I thank all of you very much for your contributions. If there is any more information that you want to give us—if you get home and think, "I wish I'd said that"—feel free to do so, if you think that it would be useful.

We have had "Your Say" sessions in the past, which have all been very informative and have helped us to take things forward by asking pertinent questions based on the information that has been given us. Today has been no different. I suggest to the committee that the clerks will go over what we have heard this morning and pull together some information so that we can ask pertinent questions of Iain Duncan Smith and the Department for Work and Pensions and get answers from them.

One of the reasons why we had this morning's witnesses is that in previous meetings concerns have been expressed about the inability of the work capability assessment to take into account degenerative and long-term conditions. On our visit to an Atos assessment centre, Atos told us that it, along with others, had raised concerns that there was nowhere in the system that would take account of people undergoing treatment for cancer. The DWP responded to that because the issue was raised. It is important that we raise these issues and ask for an explanation of why people with degenerative diseases and long-term conditions are being assessed and re-assessed, when no medical interventions are creating improvement that would lead someone to believe that they have gone from being unfit for work to being fit for work. As has been said, more miracles take place in Atos assessment centres than in Lourdes. People go into them incapable of working and come out capable of working, yet their condition has not improved. We have to get answers to such questions.

The information that you have given us today backs up the information that we had received before and gives us the opportunity to ask those relevant questions. If the committee agrees, we will send off a letter to that effect.

Members *indicated agreement.*

The Convener: Thanks very much to the three of you for coming and for the information that you have given us. I hope that the meeting was not too arduous; you have certainly helped the committee.

11:23

Meeting continued in private until 11:38.

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