Dear Secretary of State for Work and Pensions,

Employment Support Allowance

I am writing to you following the speculation in the media that ATOS wish to withdraw from its work capability assessment contract before it is due to expire in August 2015. I believe that this development presents the Department of Work and Pensions with a real opportunity to review and change the current work capability assessment with a new approach being adopted before a new contractor is put in place.

I am aware of Professor Harrington’s and Dr Paul Litchfield’s independent reviews of the Work Capability Assessment. The reviews have made positive recommendations on how to improve Work Capability Assessments. However, the recommendations have not been implemented effectively as the changes have not been felt by individuals subject to Work Capability Assessments. I believe there is much more to do to make Work Capability Assessments effective and humane.

Over the past 18 months, the Committee has heard substantial first-hand evidence from people who have been through Work Capability Assessments. This evidence is attached. These personal testimonies have provided an invaluable insight into the views and personal experiences of the application process, Work Capability Assessment and the awarding of Employment and Support Allowance. This evidence has led the Welfare Reform Committee to draw a number of conclusions and to make recommendations for changes to the Work Capability Assessment.

I would very much welcome your response to the following initial proposals and recommendations:
1. Those on ESA with long-term conditions should not be subject to re-assessments.

There has been speculation in the media that re-assessments for ESA have been suspended until a new contractor is found. In the case of those with long-term conditions re-assessments should not be reintroduced. The nature of these conditions means that people’s ability to work will not improve.

The Committee has heard from individuals about the stress and anxiety being subject to reassessment has placed on them, with many suffering further lapses in their condition as a result.

Due to the length of time from the initial assessment for ESA to the appeal process, when an individual has won their appeal they have often received a request for another assessment straight away.

A reduction in the number of reassessments would reduce the bureaucracy and therefore the costs associated with assessments for ESA.

2. People should be assessed for ESA only by health care professionals who have the knowledge and experience to understand and recognise the individual’s condition.

Concerns have been raised, particular in relation to individuals with mental health conditions, that assessments are sometimes conducted by people with limited knowledge of an individual’s specific conditions. On the ground evidence suggests that this is still happening despite recommendations from the reviews. The correct questions need to be asked so that a correct assessment of an individual’s condition can be made.

3. Changes should be made to the WCA assessment criteria.

The Committee has received evidence from people with fluctuating conditions including Multiple Sclerosis that the assessment ‘descriptors’ fail to take account of the changes in their condition. There should be further recognition of the impact of hidden symptoms like fatigue and pain in the Work Capability Assessment.

4. People who are applying for ESA should be treated with dignity and respect.

The Committee has received numerous examples of individuals who have felt ‘bullied’ and treated like ‘scroungers’ applying for ESA. Many individuals have highlighted that they paid into the welfare state over a number of years before having to apply for benefits themselves.

5. DWP communication should be in plain English clearly stating what the implications of decisions are.

Testimonies from several individuals have highlighted the lack of timely and clear information from DWP regarding their claim for ESA. Many have explained that they were confused by the information they received with some unaware that their benefit was time limited until their benefit suddenly stopped.
The Committee has also received evidence that individuals’ specific needs are not recognised in communication from the DWP, particularly members of the deafblind community.

It is important that lessons are learnt from ESA and are not repeated in the current roll out of Personal Independence Payments. Over the coming months the Committee will be monitoring the implementation of Personal Independent Payments closely to ensure that people do not face the same challenges and barriers as some individuals have encountered applying for ESA.

Yours sincerely,

Michael McMahon MSP
Convener
Welfare Reform Committee
Annexe A – Submissions from all ‘Your Say’ witnesses who have given evidence at a Committee meeting.

Annexe B – Submissions that are published on Committee’s webpage from the ‘Your Say’ long-term conditions call for views.

Annexe C – Links to official reports, papers and minutes for all ‘Your Say’ sessions. Plus a link to the official report of a fact-finding visit to DeafBlind Scotland.
Annexe A

Committee meeting - 18 September 2012

WRITTEN SUBMISSION RECEIVED FROM NORMAN GRAY

I wish to bring to your attention my concerns over the proposal to replace DLA with PIP; the criteria used to assess candidates and some of the effects of it.

Background

Our son Andrew is aged 32 and was only diagnosed with Aspergers syndrome aged 19 although he had been under intermittent Psychiatric/Psychological care since the age of three. After diagnosis he was assessed and granted DLA indefinitely. Since then he has had the occasional re-assessment. Andrew’s developmental disability stems from Aegenisis of the Corpus Collosum. Research test conducted by the Autism Research Centre in Cambridge have shown that Andrew has a very high score (33/50) for Autism traits; a very low score (7/80) for empathising and a low score (22/160) for systemising. Although he does not give the impression of having an ASD related disability these scores indicate the true level of his disability which over time with hard work by himself and his parents he has been able to minimise or mask.

Andrew benefitted from the modular nature of his educational courses and was able to achieve an HNC in Hospitality Management and employment at a nearby hotel as a function waiter. The Hotel had been briefed by Andrew’s psychologist over his management and as a result he has been in continuous employment with them for over 12 years but on a part-time basis. This work is ideally suited to him since he meets people which he enjoys; is work which has a certain degree of routine and familiarity to it and which he knows he is competent to do; and is not continuous throughout a day but involves split shifts allowing him time to come down between the shifts. Andrew works on average just under 20hrs. per week thus qualifying him for tax credits.

My wife and I are both approaching 70 and we felt it was essential that Andrew had a period of independent living under our guidance so he was able to obtain a nearby flat and live there, although coming to us for much of his day simply for company when not working. A major factor in his securing this accommodation was his DLA on an indefinite basis. His wage and tax credits gives him sufficient income to live and invest a modest amount for his future pension, while his DLA secures his accommodation. He has met a girl who also has learning difficulties of a different nature and they became engaged over a year ago. He really feels he is now living a “normal” life.

Any significant changes to these arrangements would have a major effect on him. Having studied the proposals and revised criteria for PIP I have major concerns for Andrew which I will outline below.

The Criteria.

- 7.4- Andrew’s capabilities cannot be measured in terms of percentage frequency. He can perform a task adequately over a period of time but something triggers an overload and for no apparent reason he cannot function
in his normal way. This causes him additional stress and a deterioration in an
already fraught situation.

- 7.5- Generally he can function safely even in crossing a road but as with 7.4
  there is no guarantee that he always does this safely. He cannot appreciate
  fully consequences of his actions either in terms of his own safety or their
effect on others and society.

- 7.11-Andrew requires constant reassurance through verbalising his thoughts
  and requires the answer from the person he asks. That support is different
from the support envisaged in the criteria yet without it Andrew deteriorates
quite quickly.

- In terms of the assessment criteria Andrew might score 2 or 3 in total across
  all 10 activities since they do not measure the real difficulties he has. I will
give some examples of this. Andrew can cook and prepare a meal if he needs
to but chooses not to so he gets company. He is fully aware of healthy eating
and varied diet but his problem is portion size and when enough is enough. I
activity 3 he can manage medication but his problem is his understanding of it
e.g. he thought taking a paracetamol would cure an infection which was quite
advanced because he has a very high pain threshold and did not complain
about it early enough. In washing etc he goes over the score and products he
uses last a fraction of the normal time. This is replicated elsewhere in his daily
living. In communication he is at risk to some extent through his inability to
read situations and respond to body language, especially facial expressions.
He cannot sense danger and is vulnerable in streetwise terms. In financial
matters he can handle money but has little appreciation of the value of it or
how to shop sensibly or efficiently. He cannot cope with household bills. As
alluded to above, crossing a road is generally safe but he finds it difficult to
judge distance and speed and becomes quite hesitant where a road is busy
and there is no designated crossing point. For safety he resorts to a taxi on
occasion.

- The assessment indicates that the one-to-one interview is a safeguard but in
Andrew’s case he would find it difficult to determine what was being asked of
him and respond appropriately. The likelihood is he would try to work out what
the interviewer wanted to hear and then provide an answer not based on
reality.

- I hope I have illustrated that a true assessment of Andrew’s needs goes far
beyond the descriptors outlined in the second draft of the assessment criteria
and applying them to him would give a very false picture and score.

The Consequences.
Assuming Andrew failed this assessment then he would face serious consequences.

- He would be unable to live on his wage and tax credits as at present. He
  would therefore be faced with reducing his hours to a level below 16 per week
whereby he would become eligible for income support and thus basically live off benefit. This would be soul destroying for him and he would feel a failure.

- He would have to leave his current employment situation in order to gain full-time employment. The trauma of leaving his current employment would be damaging to him. Past experience has shown that he becomes difficult when working too many hours—and this was over a short period of a few weeks. I would fear for his mental health over a prolonged period of full time work in a new environment.

- He would have difficulty in sustaining his house and living independently. The worst case scenario would be his relinquishing his accommodation and returning to the family home or local authority housing. I do not know what would happen to his marital plans.

- I am quite sure within myself that one of the consequences would be Andrew’s need for the services of the psychiatric/psychological health service at further expense.

**Conclusion.**

Whilst I am in favour of rationalising the benefit system and closing as many loopholes as possible I feel the proposals re DLA are too rigid and do not take into account the real needs of the individual nor does it recognise the complexity of Aspergers and other ASD sufferers who do not fit the norm and have a developmental difficulty rather than a learning one. In Andrew’s case he is making a very strong contribution to society to the limits of his capabilities. The proposals would make short term savings for a long term additional cost.
Dear Sirs,

I read in the Daily record newspaper today about the cross-party working group and that you wanted to hear from individuals about the benefit cuts and how they are affected by them.

I will set out below my husband’s circumstances in respect of the changes to come in Employment Support Allowance.

My husband worked all his life from 15 years old and was medically retired in 2010 by the City of Edinburgh council Occupational health, having spent 25 years working there (aged 60). This was due to him having had an accident on his scooter – having an operation to fix a plate to his leg and ankle and then after the operation taking a massive stroke. This has left him with long-term health problems and since he is now nearly 62 there is not much chance of his health improving. In fact, in the last year I have seen a deterioration.

My husband applied for and received ESA after a horrific medical which I will not go into here but I feel it was total inadequate and they did not take into account and medical information from stroke consultants, doctors, or indeed occupational health itself, which approved my husband’s early medical retirement from work. He was placed in the limited capacity for working group.

His benefit has continued from that time but according to what I am reading in the papers, from April this year ESA for people who have paid contributions is being limited to one year only and that means that when this comes into effect my husband will no longer qualify for any benefits in regards to his long-term sickness. he cannot, I understand, apply for ESA under the means tested benefits because he has a partner (myself) who is working 24 hours or more (I currently work 32 hours per week for local government on a salary around £1,000 per month after tax etc.). So as I understand it, my husband will no longer have any kind of income at all apart from the DLA he receives (which of course is being changed to PIP and that brings another lot of problems).

I cannot fathom why they are taking benefits away from people who are paid them on the contribution rate – this means that those people (including my husband) have paid into the system for many years (as my husband has worked over 43 years) will only receive this for one year and then it stops. As my husband has currently been receiving it longer once the legislation becomes law it will stop immediately and he will no longer qualify for ESA because I work (and as you can see I am not highly paid). This therefore means that for the next three years until my husband receives his state pension I am having to keep my husband and pay his share of all household expenses and such which will be very difficult for me to do on what I earn. Also, he is left to feel inadequate as he cannot contribute much and cannot understand (probably due to the problems caused by the stroke) why he can no longer receive any kind of benefits for being long-term sick and not be able to hold down a job again.

Yet all the people who will continue to receive ESA continually are those who probably never worked a day in their lives, not contributed towards it, and neither will
have their partners. Their income is not going to be changed. Their circumstances will not change at all – I thought this new system was to benefit scroungers – instead many of them will just continue as before whereas people like my husband, because they cannot for some reason be placed in the support group will continue to suffer.

So who is this change and cut in ESA hurting – it is hurting people who have worked, who have paid contributions and who have a partner – the whole situation is totally and absolutely unfair, unjust and total disgusting. So tell me why people continue to pay contributions if they may not get any kind of help in the long-term when needed?

Once this new law on ESA starts this will mean that more people who receive contribution rate ESA (and need to continue after the 1 year period) will have to lie to continue to receive it – either lie that they do not have a partner working more than 24 hours, or lie about their income or other circumstances.

In my own circumstances it may well pay me to give up work altogether so my husband can continue to get his ESA under the means tested way and for me to claim job seekers and also carers allowance (which I am to my husband but do not claim for this as I earn more than £100 per week and do not qualify). Where I ask you is the sense in that, but I may be forced into doing just that.

As I understand it, the people in the limited capacity for working group claiming ESA under contributions paid are going to be the big time losers when this new law takes effect.

On calculating our income we will be almost £400 (taking into account the increase to be paid shortly) a month worse off when my husband’s ESA stops and he cannot claim anything else. Most of the DLA he receives pays for the car so he will be left with little money for himself and will not be able to contribute to any household bills at all – I will have to meet them out of my meagre earnings. The only way round this and for my husband to continue to receive benefits is to get him placed into the support group which is very difficult – you almost have to be at death’s door before you are placed in this group – most people are not and they have to appeal, and end up waiting 9 months for such an appeal.

I really feel a lot in this system has not been totally thought through and it will affect many people’s lives (including my husband’s and mine) badly due to their cuts and changes to take place.

If there is anything at all that your working group can do on the benefit cuts then please do so on behalf of those of us who do not have a voice in this matter.
WRITTEN SUBMISSION RECEIVED FROM HENRY SHERLOCK

Inclusion Scotland have provided me with details regarding the recent meeting held with Bill Scott who was giving evidence to the Welfare Reform Committee of the Scottish Parliament about how many disabled people in Scotland on different disability benefits will lose all or part of these benefits, and how many will be further affected by the housing benefit reform.

I have been asked as part of this process, to provide information regarding my own experiences of these reforms and how they have affected my life.

Personal Information

I am a 50 year old man who is registered blind (guide dog user), has chronic heart disease, diabetes and suffers from depression. I lost my sight at the age of 31, and as I worked for a Government Department, I was kept in employment, due to their equal opportunities policies. However, when I had my heart attack seven years ago, I was finished by the Department on Health Grounds.

I receive DLA mobility and care component and have been migrated from Incapacity Benefit to ESA (Support Group).

During my migration to ESA I was continually harassed by Atos Healthcare, JCP and DWP, all of which I complained about. The processes they used and their protocols were not followed, resulting in me feeling harassed and bullied. I did not receive the communications in my chosen format and only got them when I complained. I was forced to go to a medical centre in an area unknown to me, even though protocols stated blind and deaf/blind people have the right to undergo a medical assessment at home. Those complaints were upheld and I received an official apology. This was a traumatic time for me and it left me scared about my future. ESA is a time limiting benefit, even to those of us who are put in the Support Group. In reality, this is how this benefit has been set up. The work group are limited to 12 Months on ESA and the support Group can undergo further medical assessments at any time. I was initially put in the support group for a period of approximately eight months. When I queried this, I was told, they had made a mistake and the longest anyone can be put in the support group for is three years. After this, I will undergo another reassessment. However, depending on future ESA rulings or medical examiner guidance, this could leave me being transferred to the work group sooner, resulting in ESA being removed within a 12 month period. This seems strange to me as my disability will never change, yet according to the current rules, a medical assessment can be called at any time to see whether I still am considered disabled enough to stay in the support group. As far as I am concerned this is harassment, bullying, persecution and victimisation of the most vulnerable in our society. Prior to the introduction of ESA, there were exemptions to the medical assessment process, now there are none. This means everyone has to undergo these medical assessments, even though common sense indicates no requirement. This is a waste of public spending, yet this is ignored.

It is hard enough for able bodied people to secure work during this recession, but it is so much harder for anyone with a disability. The Government appears to forget that,
and as a result, many disabled people will lose their benefit and have to depend on others for their survival. I will soon be one of them.

At this time, my benefit does not cover all my costs. I have to rely on friends and family for sensory, physical and financial support. I thought I was one of the lucky ones who saved hard when I could work and bought my own home. Now I am no longer fit to work, my benefits do not meet my needs. Unlike people in social housing, I have to pay for my repairs. I have to pay for my gardening. I have to pay building insurance and a whole lot more. Is there support for people who have their own home? No. I thought the days of the blind man begging with a cup on street corners were gone. Sadly, that is not the case. I still rely on family hand outs and additional begged support in order to live.

ESA and as far as I am aware, PIP in its introduction will never meet the true cost of disability. If disabled people were provided by the actual help they need, the true cost to the Treasury and the local authority would be so much higher than the current benefits on offer.

I fear for the introduction of the PIP, which evidently means Personal Independence Payment. However, none of the consultation papers show the application to be personal or based on independence. Once again, the questions and the weightings are all in favour of removing support rather than providing financial support. This is backed up by the fact that the main objective of this benefit is to reduce the welfare bill by at least 20%.

I fear that I will have to go through another witch hunt in order to apply for this benefit. I originally applied for DLA and due to my disability then, was awarded DLA for life. Then the wording suddenly changed on communications stating “indefinitely”.

Now, not only do they make the criteria harder they remove some of the ranges. The middle rate care component has been removed and now we only have high and low rate. Why? Two rates show no room for flexibility and are certainly not conducive to being personal.

I fear, without a doubt, I will only lose more income once I have to go through this undignified process once again. I am tired of fighting officials who seem to think they know more about my disabilities and needs than I do. It now makes me feel ashamed of who I am. I am being punished for being disabled and feel powerless.

Being blind is an isolating disability. If my benefits are slashed in any way, I will become even more isolated. I would not be able to afford to use my computer. This is the only true way of providing me with information and communication. I would not be able to afford the Internet, which will cut me off from family and friends. I would not be able to afford the additional high cost of assistive technology I use, which will leave me in danger. I will not be able to afford the support I need for shopping, gardening, socialising, banking, reading mail, getting places like hospital, dentist, barbers etc.

Many benefits have passported support, such as the national entitlement card, which acts as free access to buses and trains. As a blind person, I was proud of the
Scottish Government for recognising the fact that blind people require a companion in order to get about and participate in society. However, if this changes with the new rulings, I could find myself without this support. Without this card, I would become bound to the area I live in, which will in turn lose my rights to a social life, family life, health, daily living activates. The entitlement card is awarded based on the benefits you receive and one of them includes DLA. Changing to PIP could have a dreadful impact on peoples mobility, jobs, involvement, health and social aspects.

I only wish the Government would look really close at people’s disabilities and see the true disabling factors. Disabled people are still fighting for equality to jobs, access to the built up environment, access to information, access to social lives, access to housing. The barriers are still there and with this recession, no money is being spent to remove those barriers. How are the disabled ever going to get equality?

As a blind man, my medical assessment declares I am mobile because I have a mobility aid, my guide dog. I am mobile, but not fully independently mobile. I am only mobile in areas I have knowledge of. I am only mobile if I remember my route.

I am not mobile if crossings don’t work, or during bad weather in wind and snow, or in areas I have never been to, or if my guide dog is out of commission. The questions and weightings should not be put in such a way which favours an outcome of removal of support, the questions should surely be in favour of positive outcome for the customer/claimant. This needs to be examined under OUR human rights and the UK’s Equality Act 2010.

I am a proud man and would love to work for a living. However, the true facts are, employers do not want to employ disabled people. There are no real incentives for employers to employ disabled people. There is no strategy in place to help disabled people get jobs and retain them. Even when I was in employment with an equal opportunities employer, I did not have all my needs met. Communications were always in print format. Meetings were held and my needs ignored. Although most understood I used a screen reader which is a slower process to listen to it, as there is no facility to speed read, I was still expected to meet the same targets as someone who could see. I had to work harder and longer, just to keep myself in work and as a result I ended up with a heart attack due to the pressures. Not just doing the job, but, travelling to the job, travelling within the job, coping with my disability and organising workloads. When you are the only one who is blind in the work force, you are even more isolated. There is no one who understands your needs or the support you require. I loved my job. However, I did not love the isolation, fear, bullying and hardship it brought.

It truly is a sad reflection of any Government that refuses to see the true fear it has put the most vulnerable in our society under. In my opinion, it is simple persecution. We did not choose our disabilities.

We need support to ensure that the most vulnerable in our society is not the hardest hit. Many of our disabled people are having their incomes slashed from anything between 20 to 100%.
It would be good to see the Scottish Government take positive proactive steps to help protect its people from this persecution. It would be a significant step forward to see the Scottish Government involve disabled people in any process which will affect their lives.

I hope this has given you some insight into the fears I have for my future. This just the tip of the iceberg and I am sure there are many stories out there from people similar or indeed worse off than myself.
WRITTEN SUBMISSION RECEIVED FROM MARLENE HEPBURN

My name is Marlene Hepburn. I have Multiple Sclerosis and have recently been reassessed for the new benefit replacing Incapacity Benefit. I was retired from my job as Senior Teacher on grounds of ill health 5 years ago. My experience of the new work capability assessment was dreadful. The first appointment was cancelled at the moment I turned up for the appointment. A second appointment was arranged adding to my already heightened stress level. I found the actual assessment very stressful and was devastated to be told that as a result of the assessment I no longer qualified for the new benefit-I would be moved onto Job Seekers Allowance. I have a copy of the assessor's report which in my mind place huge emphasis on how well I looked and how well turned out I was. I look well because I self-manage my condition well with the help of medication-injections of Interferon 3 times weekly. I also try to lead a healthy lifestyle being pro-active in my approach to this disease. My fear at this precise moment in time is that this whole experience will trigger a relapse. The emotional stress has been enormous and has had a detrimental impact on my health I am in the process of requesting a reconsideration/appeal further adding to my worries. Financial worries were added today with a letter from the DWP confirming cessation of my Incapacity benefit. I appreciate the benefits system needs to be reformed but not to the detriment of genuine claimants.

Update

Following my communication with regard to my experience with atos I thought I would update you on the latest turn of events. On Saturday I received a response to a submission on my behalf for a reconsideration of the decision - a 71 page response which said there was no new evidence to overturn that decision and I could now go to appeal. That was Saturday and since then my level of anxiety has reached an almost unbearable level. I had just had my regular checkup with my MS Specialist Nurse on the Friday and she had advised me to keep my stress levels down as it is a well established fact stress has a damaging impact on MS. I am trying to control the stress but I have now reached my limit and I do feel extremely vulnerable and anxious as to what my MS will do now. Welfare reform is a good idea in principle but when it has such a negative impact on the vulnerable then somebody needs to listen and action needs to be taken to protect people like me. I worked as a teacher for many years and was retired through ill health - MS is incurable - there is no miracle cure. My latest "sick line" from my GP sent to the DWP just days before this latest bombshell was for a year - his opinion apparently counts for nothing. I would appreciate a speedy response to this account of the impact the reform is having.
WRITTEN SUBMISSION RECEIVED FROM LESLEY MCMURCHIE

My husband was retired from work five years ago having been employed as a social worker since 1973. He was never off sick until he was retired due to permanent incapacity following a mental breakdown due to workload and family problems. He also has some physical problems; asthma, arthritis in his knee, spine and neck as well as high blood pressure and swelling in his ankles. He has limited rotation in his wrist and swelling in his fingers as well as pain in his wrist following a fall in the garden when he lost concentration and fell over a garden pot. Mentally he is very fragile; he is virtually reclusive only going out accompanied by me. He is socially withdrawn too; when family visits he removes himself from the scene and goes upstairs to his study. He find organising himself very difficult and I prompt him regularly when I am at home. He loses items regularly and I often find that he is looking at them but does not see them, things like his glasses and letters. He regularly drops his medication and I often find pills on the floor and when I ask him if he has taken the correct dose he is unable to tell me. When I am not around as I work 5 days he sits in his dressing gown, unwashed and undertakes no tasks around the house.

He was able to claim Incapacity benefit and has had his health reviewed by DWP annually since first claiming incapacity benefit. Each time he scored sufficient points; that is until he was assessed in June 2012 for ESA.

He had undergone three re-assessment prior to the June assessment. The first two were carried out by a DWP doctor. These two assessments were conducted in an atmosphere where my husband was able to discuss his illnesses and how they affected him without sticking rigidly to a set question and answer framework. The doctor clarified my husband’s answers before recording them and was sensitive to my husband which I felt helped a great deal as he gets confused and loses concentration during longer discussions. He clearly was experienced in handling patients with mental health problems. These two assessments fully recorded my husband’s medical conditions and when we sent for a copy we agreed fully with the assessment. The assessment before June 2012 was carried out by filling in a form and he received notification that he had scored sufficient points and did not need to attend a medical.

His health over the last year has deteriorated and he is presently waiting to see a psychiatrist but he has been told the waiting list will mean he may have to wait another 12 weeks minimum, from this fact alone his mental health alone has deteriorated since his last fit for work assessment. He has also broken his wrist last summer and has a metal plate fitted and now has limited mobility using his hand due to swelling and pain. He cannot tie his shoe laces and button shirts due to his wrist pain and swelling in his fingers.

On the day of the assessment he had to take additional medication (8mg diazepam) before he was able to leave the house, take some before entering the medical (4mg) as we had to wait for over an hour as there had been a mix up in the booking (which was commented as a positive in the final report!) and had additional medication (4mg) on arriving home. There was no opportunity to reveal this at the medical as the structure did not allow for deviations from set questions. Indeed when he said that he was having a bad day this was recorded but not explored or discussed.
The assessment itself was conducted in a manner geared to clients with physical disabilities with only 5 minutes out of the 60 minutes being devoted to his mental health. None of his answers were recorded accurately; the report was a cut and paste job of small parts of answers which were geared to showing him as having no difficulties i.e. when he was asked if he walked to a local shop he answered that he had only attempted this twice in the past 3 months and has found the ordeal harrowing...this was recorded as able to walk to the local shop. There was no follow up questioning of why he found this harrowing which could have illuminated his mental health problems. I also felt that by this time we had been there for nearly an hour (nearly two and a half including the wait) and my husband was struggling mentally to cope but was putting a brave face on it and was desperate to get out of the room. I also felt the nurse needed us away as she had other appointments. She also made a comment about my husbands skin tone saying he has a good tan, which I took to mean she thought he spent his time out of doors enjoying the sunshine. Last June was a particularly wet month and my husband’s highly florid skin tone is a result of steroid medication he takes for asthma. I was hurt by this thoughtless comment but did not respond as my husband was clearly feeling the pressure of the assessment and would not have coped if I had questioned the nurse about this.

Needless to say when we received the result he was fit for work...it was as expected as it was obvious from the medical examination and the subtle negative feelings projected by the nurse!

We went to citizen's advice for advice re an appeal and were advised to see our GP and get a sick note and appeal the decision. We subsequently visited our GP who refused to give my husband a sick note as he said if he has been assessed as fit for work by ATOS then he must be. After a lengthy discussion he gave my husband a sick note with fit for part-time work only on it.

We took this to the DWP and were told there were no facilities for this...you were either fit for work or not! He was told he had all his contributions paid so there was no point in claiming esa as he had a pension. Furthermore they would not help him find part time work as they were too busy finding work for others who needed full time employment who were claiming ESA.

This is suppost to be an improvement in the Benefits System...words fail me!
I am a veterinary surgeon who has been unable to work for the last 9 years. I received Incapacity Benefit at the higher rate for 8 years. My difficulties started when I was sent for an ATOS assessment. I suffer from Fibromyalgia and several allergic illnesses. I travelled into central Glasgow by bus and train and then had an hours wait for my appointment. By the time I was seen I was suffering severe pain and discomfort. My memory is not totally reliable due to my state, but I think the interviewer offered on three or four occasions to stop the process due to my obvious distress. I stated that I would be just the same at any subsequent interview, so I would rather proceed and reduce the overall amount of pain that I would suffer. Towards the end of the session she stated that she would not conduct the physical examination as this would cause me even more distress. She then enquired how I was to return home. When I stated that I would have to use the train and bus, she very kindly organised for a taxi to take me to my door due to the serious suffering that I was experiencing.

Given all these facts, I was totally incredulous to be told by a telephone conversation from a DWP employee that ATOS had assigned a score of ZERO! This caused me enormous distress as it effectively labelled me as untruthful and completely impugned my honour. When I informed the person from the DWP of the circumstances of the interview outlined above, he just repeated over and over again “So you say” as if I had invented the whole matter. I asked him to seek proof from ATOS as to the veracity of my statement given his scepticism. My incredulity was further increased when I was informed verbally that my written submission had been assessed and the DWP had allocated a score of 66!

During the conversation I was eventually informed that they would reassess my application if I could organise written statements from medical practitioners. Reports were arranged from my Occupational Therapist, Consultant Physician and my GP. All this information was just enough for a DWP employee to award the minimum 15 points for me to qualify for the Work Related ESA. However this only lasts for 1 year and then stops. I find living a major difficulty and work would be an impossibility. Given this, I had to appeal the decision and will have to attend a tribunal in order to receive the Support Group status. The attendant stress that this process has caused over the last 11 months has caused a real worsening of my condition. I have suffered multiple infections due to stress reduced immunity and I have been placed on antidepressants.

Whilst waiting for the appeal I was phoned by an employee DWP, to be told that he would not have even placed me on the work related group, essentially implying that my appeal was useless. The following day, after a prolonged wait, I collapsed in the doctor’s waiting room and required a 999 ambulance call out. The diagnosis was a severe flare up of my condition caused by “stress”. I believe that the call from the DWP was a major contributing factor.

My condition continued to deteriorate in that I have begun to use a wheelchair.

After waiting seven months for the appeal and only 2 weeks after the last call from the DWP, I received another call from the same operator to say that he had received a letter from my consultant psychiatrist and had phoned her personally. As a result of
this phone call he was placing me on the Support Group, ESA! And that I would not be bothered until December 2014, but even then I would only require to resubmit the psychiatrists report and the Support Group status would be renewed!

The following week I received a letter indicating that I had to attend another ATOS assessment! As you may imagine I was stunned and extremely upset. I contacted the DWP to be told that this was an error and they confirmed that I was indeed on the Support Group. I have subsequently received another letter indicating that I was on the Work Related Group and I again had to check that this was another mistake.

When asked how I spend my time, I reply that actively trying to maintain my sanity accounts for the majority of my limited reserves of energy.

I have tried to present the facts that are hopefully relevant to your inquiry, without being too descriptive of the physical and emotional state that I suffer. Even composing this short letter has caused stress, which has the consequence of worsening my condition.

I will do my best to help with any additional information that you may require.
Committee meeting - 10 September 2013

WRITTEN SUBMISSION RECEIVED FROM ANNE BRADLEY

I read the article in the Evening Times regarding the “Bedroom Tax” and I believe that this “Tax” is in breach of everyone’s Human Rights and it should be dumped.

I have a two bedroom flat in the Cowcaddens area of Glasgow which I rent from Queen’s cross housing association and letters have been delivered from the housing office with advice on the bedroom tax, cost and payment methods, these letters informed me that the cost of this “Tax” is to be £43.64 per month. No further contact has been made by the HA on this matter.

Since receiving these letters, I have contacted the ha to make them aware of my request that I be moved to a smaller property but in the same area, I have submitted a completed transfer application for a move and have also submitted an application for DHB but I have been advised by the HA that they do not know when I would be likely to secure a transfer since there are NO smaller properties available in the area I wish.

The suggestion was made that I could take in a lodger but I would NOT even consider a lodger as, although this would stop the bedroom tax charge, I would not consider taking a stranger into my home. Taking in a lodger would create its own problems. The housing benefit is already being reduced for the “BEDROOM TAX” this would be reduced further because someone was living with me.

I am in receipt of E.S.A which is paid on a fortnightly basis, at present, which enables me to pay utility bills, insurance, water charges by direct debit since I always know that the benefit will be in the bank in time for this but after buying groceries there is not much of the E.S.A left. Were I to take in a lodger, the E.S.A would be reduced further or possibly stopped creating more of a struggle.

Since there are no smaller properties available I believe that as a result of this unjust “BEDROOM TAX” and the fact that in having to pay an extra £43.64 per month, which will create an even bigger struggle and I have heard that the council tax benefit has been effectively abolished which means that a payment of 10% will be expected for this as well as the bedroom tax.

The struggle will become much worse when the Universal Credit is introduced since the payments for rent and the benefit will all be paid into the one bank account and this will create even more of a struggle.

I believe that I am being forced out of my home and prevented from having a family life since I shall not be able to have family members stay overnight or at weekends etc. In order for me to find a smaller property to rent and since there are no smaller properties available in Glasgow, I shall be forced to look further afield for a suitable property and I may have to apply for a private let which will have problems of its own.

This “BEDROOM TAX” is unjust and is separating me from my family since I have to move to where I can get a smaller property.
WRITTEN SUBMISSION RECEIVED FROM LINDA KENNEDY

My name is Linda Kennedy. I will be 58 years old come the 2\textsuperscript{nd} March. I have not worked for the past eight years. Six of those years, I was a full time carer to my late husband who passed away on 25 February 2011. We were offered help with the care, however, we both decided I would take care of him, giving him the dignity he deserved.

Like many others we always worked. My late husband had a saying “everybody must put into the pot, if they don’t, there will be no pot (tax and national insurance). I still have those values.

At present, I suffer from anxiety and panic attacks but I am getting help for this. My total income is £72.07 per week (which is my late husband’s work pension). The powers to be take £1.07 off as the government says I only need £71 per week to live off.

My problem is that I live in a 3 bedroom house alone. My kids have moved out and into their own homes. I had a visit from my housing officer telling me it will be just under £100 per month extra, but the rent rise in April could take me to just over £100 per month. He informed me I could either take in family members or a lodger(s) to help pay the bedroom tax or move to a smaller house.

I fear what the future holds and question what do I do next, where do I go, where will I end up? I have lost everything, my husband and now potentially my family home.

I know I am only the tenant, however, I class this house as my home with many great memories. I know my neighbours and they know me. Ultimately, I feel safe here.

To end this narrative debacle, I was told “well you should have bought your house”. Like many others, we worked hard, paid the bills and helped the family through their formative years and education. I refuse to beat myself up for being widowed and not a homeowner. Both my kids are fortunate to be in full time employment and not on benefits. They feel angry and are disillusioned that their mother can’t get a bit of respite from “the pot”.

WRITTEN SUBMISSION RECEIVED FROM SCOTT WILSON

Welfare Reform and the Underoccupancy Charge

I would like to tell you about my experiences of the welfare system, and particularly how the underoccupancy charge will affect me and my family.

My name is Scott Wilson. I am 46 years old, and was diagnosed with younger onset Parkinson’s five years ago. I had always worked hard since I was 16. Because of Parkinson’s, I had to give up the successful gardening business I had built up over many years, and my decade of service as a reserved firefighter in South Lanarkshire where I live.

One of my Parkinson’s symptoms is a very severe tremor which got worse over time and didn’t respond to medication. I had to have brain surgery which has helped to control the tremors, but I still have other Parkinson’s symptoms. Parkinson’s is a progressive condition, so it will inevitably deteriorate, and stress makes my symptoms much worse.

When I gave up my business, I had to apply for benefits to help support myself and my family. I have a seventeen year old daughter and a ten year old son, who has a severe long term medical condition. The last thing I wanted was to have to rely on Government Benefits, but I felt that at least I had worked hard and contributed to the system before I became ill. I had lots of support from Money Matters in Lanark, who made sure I claimed the benefits that I was entitled to, including incapacity benefit, income support and an indefinite award of Disability Living Allowance.

While life was not easy, and I knew that I had an uncertain future because of my health, knowing that I could stay in my home and had some money that I could depend on made it much easier to cope.

Since the Welfare Reform Act has come in, I feel really stressed and anxious at the thought that someone who has no knowledge of my condition will re-assess my benefits, and that they could determine that I am fit for work, or that I not affected by my Parkinson’s, and that I could lose the benefits I depend on. I was broken-hearted to have to give up my business, and would love to be well enough to work, but my Parkinson’s makes it impossible.

I recently separated from my partner of nearly 20 years, partly because of the stress that Parkinson’s has put on my family life and relationships. It has been a very difficult time for all of us, but we have maintained regular contact and my ex-partner and I continue to share the parenting of our children. It has been made worse by the fact that I have had to apply for some different benefits, and in particular the underoccupancy charge / bedroom tax that will come into force in April.

I have lived in my home for 25 years. We had to sell it back to the council because of financial hardship.

I was shocked when a council employee phoned and told me that my housing benefit would be cut to the equivalent of a one bedroom home and that I would have to find the additional money from my benefits to pay for two bedrooms. I was stressed enough about how I was going to pay for my heating, food, transport and other necessities, and this information floored me.
When I asked for more information, the council employee told me that I had three options:

1 - The council could look at re-homing me in a one bedroom flat. There are very few of these in my home town, so I might be relocated somewhere else, which could be many miles away. This would put me away from my support system – including my friends and family, and the health centre that deals with my day-to-day health needs, where the staff know me and are able to give me the help I need. And I might not even be able to access a one bedroom flat in another town as there are lots more people needing one bedroom homes than there are flats available.

2 - They could also look at house sharing with someone else who was on benefits. This would mean sharing my home with a stranger whose background I didn’t know, and possibly exposing my children and myself to risks

3- That if I did stay in my house I would have to find the shortfall in the rent myself from my other benefits

I asked the person on the phone about how I could have my daughter (and expected grandchild) or my disabled son to come and stay with me if I moved to a one bedroom flat, or shared my home. I asked where were they were expected to sleep, and was told “have you never heard of inflatible beds?” This took my breath away. I was literally speechless that the love and support of my children and their need to spend quality time with their father could be so casually dismissed.

I also enquired about what happens when my Parkinson’s gets worse - as Parkinson’s is an incurable degenerative disease, I will progressively become more disabled and I am likely to need more support over time. Because I am no longer with my ex-partner, I may need a live-in carer to support me. I asked where a carer would stay. The reply was “we can cross that bridge when we come to it.” So I may now be unable to make any plans for the future until I am really unwell when I might not be able to access the type of accommodation I would need.

I was stunned by the lack of sympathy and understanding for people in my position. I am so anxious about the whole situation, and I am concerned about the effect that this is having on my Parkinson’s. This seems to be being rushed through, and it feels as though the Government in Westminster has not thought through the consequences for people like me who the benefits system is supposed to help. I can’t believe that this is really being suggested, and hope that people will take notice, do what is right, and call a halt to this process.
Committee meeting - 18 February 2014

WRITTEN SUBMISSION RECEIVED FROM AUDREY BARNETT

I worked for the DWP 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 which are straightforward and consistent. They are not designed to deal with fluctuating conditions such as Multiple Sclerosis (M.S) or Systemic Lupus Erythematosus (S.L.E.) both of which I suffer from. They 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 it was very hard for me to give a full picture of what it’s 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, this is also 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 can’t 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 this form made it worse. I also suffer from Benign Paroxysmal Positional Vertigo (BPPV) and this is brought on when I look down; completing this form made the dizziness come on and took quite some time to pass. I did the form over a month to try to avoid this but I had so much writing to do that it was still enough to set it off. As a result I couldn’t do much for a few weeks, my husband and mum had to do even more for me, I couldn’t go out and certainly couldn’t drive. It is common knowledge that most people get put into the WRAG group for ESA and this 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 8 different Doctors and Nurses. I explained about having to give up my job with the DWP and that I was awarded medical retirement. I also enclosed a letter from my GP stating that I have both MS and SLE and that both are progressive, unpredictable, ongoing and incurable illnesses which I will never get better from. She stated that ongoing 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/ATOS to contact her if they required any further information – they did not do this, in fact they did not contact any of my medical professionals. In time I received my decision letter from the DWP telling me I had been put in the WRAG group. Enclosed with the letter was a leaflet ‘what to do if you think your Jobseekers Allowance decision is wrong’! I couldn’t 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 this letter brought on a full blown
anxiety attack, something I hadn’t had for some time and they are horrid. I wasn’t fit to do anything about it that day but next day I phoned the DWP for an explanation, I eventually got through to them and was told somebody would phone me back either that afternoon or the next morning – they didn’t. 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 3 times, the 3rd message she left was very stroppy saying that I had asked for them to phone me back that day but hadn’t bothered to wait in!! I phoned them again and managed to talk to somebody who said they would send me out an explanation of their decision. All they sent was a single page telling me I had been placed in the WRAG group! I arranged to go and see the CAB, the lady was horrified at how I had been treated and she took on my case. She suggested 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 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 advisor, he said he would postpone any action until the result of my reconsideration came through. I waited and waited to hear from the DWP to see if the decision had been changed – I never did receive a notification letter. In May I sent the DWP details of the rate of my occupational pension for this year and when they wrote to me to tell me what my ESA rate would be with this adjustment I noticed on the letter the words ‘because you are in the support group....’ I was so relieved to read this but 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 didn’t want to be defeated. Being made to feel like a scrounger by having to virtually beg for benefits from a system I had paid into for many years is horrid. I certainly never chose to have health problems but the way ATOS & the DWP deal with people now you have to justify being ill. I fully understand that benefit tests have to be done but if you get to the stage where a chronic, progressive illness has caused you to have to give up your career then common sense should come into it and you 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 re-assessments.

Things for disabled people are only going to get worse when we are changed from DLA to PIP. A very high number of people are going to find themselves on less money than at present and with the government estimating that 1 in 6 will lose their motability cars 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 they depend on and getting help they require. It will also affect their entitlement to some other benefits and things like bus passes, blue badges etc.
Employment Support Allowance

I have supported several people who suffer severe mental health problems but scored zero points in applying for ESA. In each case they were supported by evidence from GP, CPN and / or Senior Mental Health Support Worker.

In the first case to reach appeal stage, 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; made to feel like frauds for suffering poor mental health; 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 etc.

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.

Personal Independence Payments

I have assisted 5 Service Users in applying for PIP: the first was registered on 11 July 2013 and PIP awarded approx. 20 Dec 2013 (A delay of 5 Months)

The others were registered on 26 August, 01 October, 02 October 2013 and 20 January 2014. None of these have yet been decided by ATOS / DWP.

These delays cause frustration and anxiety and suggest that the PIP decision system which has only recently been introduced is already in serious trouble.

Hope this is of assistance - please let me know if you wish any further information on any of the cases.
WRITTEN SUBMISSION RECEIVED FROM ROSENA MCKEOWN

I am a Polio Survivor, 54yrs old and am unfortunately now suffering the effects of Post Polio Syndrome (PPS) this is also referred to as Late Effects of Polio. The Scottish Government has released a report on this


I was discharged from medical/orthopedic care age 15. I like every other survivor was told to 'get on with it' and forget I ever had Polio. This was not as difficult for me as it was for others, I was 'rehabilitated' and no longer used sticks or calipers.

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

My last employer was Glasgow District Council who, despite their efforts to assist me to stay in employment with ACCESS to work, changing my job description etc., I found myself unable to sustain my job. The fatigue and muscle weakness had become incompatible with even my job-share position.

The chance of early retirement became available and I applied, I felt that this would be the best option rather than being possibly made redundant due to sickness absence.

I first encountered the WCA in 2008 when I went to Jobcentre Plus. I was interviewed and they explained to me what would be required and that a letter would be sent in due course.

The appointment came quite quickly and I didn't suffer any apprehension about the assessment, my GP and the Consultant I had been referred to agreed it was PPS.

The Doctor I saw at the first assessment was courteous and seemed to have an understanding of the problems which were developing, his report reflected this, he stated I had Post Polio Syndrome. I have a copy of this report should you wish to see it.

From then I was put into the WRAG group receiving ESA, to be reviewed in 12mths when my contribution had ended.

My second WCA came 18mths later. I had a little apprehension when attending this assessment, mostly due to the information of other people who were being found 'fit for work'.

I was greeted at the assessment centre by a Physiotherapist, I did ask her when we were seated in the room if I should not be seeing a Doctor as I had a Neurological condition, her answer was that she was allocated my case.

We had only begun the questions she was asking when she stated she would have to stop the assessment as I was 'flagging' up warnings with my answers and would need to see a Dr.
I did get very upset at this point, I had no idea what her warning flags were and she didn't explain it to me. She left the room in search of a Doctor who might be free. When she returned she said I could either wait until a Doctor was free or re-schedule the appointment. I told her that I honestly didn't think I would be able to return there given the stress/distress I was now in, I also stated that I didn't think I would be able to sit in the waiting area given the stress/distress 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, this is something I've never suffered from. I had stated in my ESA50 that the fatigue when especially bad can cause problems with recall and that I find myself unable to do anything.

This Doctor in my opinion, made no effort to hide his annoyance at being called to see me. He was very curt to the point of rudeness. 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, this was extremely distressing as I have a splint on my right leg to the knee, then a knee brace, it is very awkward for me to get up and down but I did this.

This Doctor actually laughed at me when he asked what I did if I found I couldn't push the hoover, I told him I would tend to pull it backwards.

After the assessment, which lasted less than 15mins, I left in a very distressed state.

I was informed by the DWP that I had been found 'fit for work', I informed them immediately that I would be appealing this decision and requested a copy of the Medical Report from ATOS.

To say I was shocked at what I read in this report is an understatement, it was as if I was reading about someone else. At the end he had stated I was suffering from Back Pain.

As soon as I was able to I reported this Doctor to the GMC, his report had only a cursory mention of Polio, no mention of new muscle wasting, fatigue or the other symptoms he had been informed about. I have heard no more from the GMC and can only assume that they are taking the complaint no further.

I took the decision to Tribunal, I had the decision overturned with the stipulation that I do not be assessed for 24mths.

My condition has deteriorated markedly since, I now have to use a walking stick as the muscles in my right thigh have wasted so much my balance is impaired.

I was approached by my Housing Association in December 2012 as I had a 3 bedroom flat, they asked if I would be prepared to move to a smaller property. I was agreeable to this as I was on the first floor and would have been approaching them 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 have been extremely helpful, they have a Benefits Advisor and try to help their tennant's as much as possible. I filled out the application and kept my fingers crossed. My Housing Officer called in April, she said she had a property in mind but there might be a delay of around 8wks. Unfortunately due to
circumstances, I did not actually 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.

This new tenancy is exactly what I need, the Housing Association have 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 were fully aware that he would be leaving anon, their Benefits Advisor 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 do need help with shopping, changing bedding etc 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 this now.

I expect to be re-assessed for ESA in 2015. I will also be migrated to PIP at this time I suspect as I have an Indefinite Award for DLA. With all the changes taking place and the 20m rule that has been introduced, I cannot be certain that I will be awarded the 'enhanced' rate which would enable me to keep my Mobility Car, thus losing my independence.

I failed to receive the Discretionary Housing Payment when I applied in April as I did not fit the criteria, I shall apply again but I'm not confident that I will fit the criteria now.

Given all of the above and taking into consideration the cost of energy/fuel/food all rising, I feel that the future looks rather bleak.
Having received this link via Autism Rights Group Highland (ARGH), I wish to add my experience to the collection.

I am 41 years old, female and living alone in Aviemore. I have Asperger’s Syndrome, depression, fatigue and am now being investigated for borderline personality disorder, though I and my support workers have doubts about this diagnosis and I suspect that the psychiatrist suggesting it is under pressure to get people off benefits as he tells me it can be cured now by a course of therapy which is intended to force me to think a different way. He seems sceptical about the futility and potentially damaging effect of enforcing this on someone with autism, not to mention the stress the very idea of it is causing me (I have had increased anxiety and sleep disturbance since this issue arose).

I receive DLA high rate care and low rate mob, with the transition to PIP due to be triggered any day now; I am in the support group for ESA having just succeeded in having that extended for another year after an initially very hard fought two year award. I live independently and do voluntary work but my GP is very concerned about the effect on me if this evident stability is threatened because it makes the benefits people disbelieve me and not appreciate that I would instantly deteriorate into crisis if I were pushed into looking for mainstream employment. The regular reassessments for both benefits are a huge worry as I stand to lose up to 50% of my income if I do not get the enhanced rate of PIP, because of the associated disability premiums. I am not affected by the bedroom tax as I am in a one bedroom rented house and the rental is expected to be long term but it is with a private landlord and the day will come sooner or later when I have to move. Due to the lack of one bedroomeed social housing it is likely I will be affected by the bedroom tax at a later date. I could absorb it if my benefits remain at their current levels but not if I lose much of them. This is another added worry, as well as the shortage of housing in Highland and my single, no children status which means I will not be a priority despite my autism and it is unlikely that mainstream authorities will appreciate that they cannot force an autistic person into shared accommodation and I would be unsafe in emergency homeless accommodation because of my inability to judge social situations and read people as well as my autism and wariness causing me to seem aloof / snobbish, which I am not, but which would trigger anger and resentment amongst people who are sensitive to such behaviour from others.

The effect of the welfare reforms on me is currently in the form of continuous worry and stress as well as the morale and energy drain of the ongoing awareness of the public backlash against “the Jeremy Kyle demographic” of people on long term benefits and that we are perceived as scroungers when in fact I work as hard as I can within the confines of my fatigue and am holding two voluntary jobs, at the new Autism Initiatives Highland one stop shop for autistic adults, which I helped to found, based in Inverness and at the Strathspey Steam Railway (non public facing
office work) here in Aviemore, as well as periodically helping friends and contacts with online research, creative ideas etc for their own related projects.

Thank you for taking the time and trouble to listen to and collate the views of those of us affected.
WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM EVELYN BURROWS

Welfare reforms have left my husband and I on our knee’s.

I have been very ill over the past five years - Depression, Anxiety, Hyperhidrosis, Parathyroid, Thyroid, and a few others. I have worked from 15 to 58.

I had been on long term incapacity and was transferred last year to ESA. Not being someone who used the benefits system I wasn’t aware of the benefit being for only a year. My benefit ran out in September and I didn’t receive a letter to tell me it would be stopped. I now find I am entitled to nothing. Not even if I register for JSA.

My husband has a small pension of £150 per week he has had to retire due to Heart conditions, diabetes and claudication. He cannot work and cannot claim any benefits. My husband has been told it’s now his duty to keep me on his £150. He doesn’t claim benefit as ATOS found him fit to work two years ago. Two weeks after that finding he had two stents fitted into his heart. He doesn’t qualify to sign on for JSA either.

We are two Adults who have worked all our lives and we are both not able to make a claim for anything. Welfare Reforms......that’s a joke. Where is our help?
I know you probably can’t help me but I just wanted to share with you just how tough I’m having it at the moment.

I’m a single mum with two children aged 9 and 13 who has been off work sick since July 2013 after a simple operation brought on Chronic Fatigue Syndrome. I was working with the Children & Families East Neighbourhood Admin team and since July I’ve had the luxury to go from full pay, then half pay, to SSP to now having to apply for ESA.

Life for me went from being a busy independent mum hardly ever in the house, going out at the weekends with the kids to the cinema etc to having to sleep downstairs in the living-room because I can no longer cope with the stairs, being constantly tired, never getting out the house unless I use a wheelchair as walking is too tiring to never doing anything at the weekends as the town is too noisy, bright and tiring. Recently the furthest I can go is Cameron Toll and even that has to be when its very quiet due to sensory overload.

I also recently was diagnosed with a hearing impairment so I’m now waiting on a hearing aid. You could say life for me is just peachy!!

We’re all suffering because of this illness more-so my kids who now have no social life and have had to virtually take on my role having to cook meals, clean up the house etc as apparently there is no facility of help like that anymore.

I’ve applied for a house move to a ground floor bedroom/bathroom or bungalow on the East side of the city near my only family members who can help, my step mum and dad, to reduce the pressures put on my children but as I’m looking for almost like for like, according to the council, I need to look at house exchange rather than having to 'bid' for an acceptable house as that could take years and quite frankly my kids would loose their minds if they had to wait that long yet there is no one willing to exchange with me who have the facilities I am now requiring. The best place for me would be the Thistle Centre yet according to the Council I still have to Bid for these properties if and when they come up.

I was surviving 'just' financially when I still had working tax credits on SSP however they stopped this week and I was initially told I would get £106 a week ESA however a letter today states I am only getting £71.70 a week.

How the state can penalize a person who wants to work but is off sick through no fault of their own I do not know :( It actually stinks that I’ve worked hard to ensure I made my kids proud of me. I went to college for 4 years whilst taking regular Pseudo seizures to gain an HND Admin & IT degree with Merits to ensure I got a good well paid job. I bought and paid for everything in my home - NOTHINGS on
credit, except the blasted treadmill I recently bought from Littlewoods in the hope that it would get me better thinking exercise would cure me, how wrong was I, yet I'm now in a position where I'm having to beg for food because the money the governments giving me is not enough to cover the bills that I'm locked in contracts with.

I've tried to reduce the payments I make as much as possible but I can't reduce them any further. When I was working I took out a loan for a holiday with the kids and a contract phone as I did not foresee being so ill now, how would anyone. Boy am I regretting that, I'm locked into 2 year contracts with most bills so cannot cancel or reduce payments etc

Tonight I redid my budget using the figures I now have and I am now struggling financially. I've gone from a wage of £1100 a month to a benefits income of £286.80 a month. How anyone expects someone to live on that I do not know. Could you? I really would like to see you try!!

When I wasn't working I got:

£90 odd a week Child Tax Credit, £30 odd a week Child Benefit and for myself just over £100 a week Income Support

I start working and earned:

£150 odd a week Child Tax Credit, £450 odd a Month Working Tax Credit, £33.70 a Week Child Benefit and a Wage of £1100 a month

I became ill and unable to work through no fault of my own I'm now on:

£98 a week Child Benefit, No Working Tax Credits, £33.70 a Week Child Benefit and £71.70 a week Employment Support Allowance

So you tell me what you think - Somethings not right there at all!!

I even did a benefit check as I thought someone somewhere must have done something wrong to make me survive on that amount however nope all the figures check out on both the government one and entitled to. I cannot yet apply for the new DLA scheme until I get my specialist appointment and for them to give me a letter confirming I have CFS/ME so in the meantime I am struggling, mind you from what I've read I'd be lucky to get anything from the new scheme.

I've been savvy with my money as much as possible even getting my kids to take packed lunches to school so I didn't have to pay school dinners as according to Edinburgh Council I wasn't entitled to Free School meals on SSP despite my severe drop in wages. However I'm not making ends meet and have been relying on putting things on my credit card again when things were tight more so at Christmas when the kids expected some form of presents. Its a vicious circle, I pay off the credit card with money for food, bills etc, I have no money for food or bills etc so I pay by credit card.
My condition is exacerbated by stress and by god this is not helping.

I was told to consider the foodbank before Christmas and up until now I was trying to tell myself I could manage and that I really wasn't in need for it, however tonight I'm sitting having to tell my kids we are in serious financial problems and to cockanny with food we have as I can't afford to buy stuff etc. As I live in Hyvot Loan my nearest one according to Google is the South East Branch and so tonight I've had to suck it up and email them begging for help.

Never have I been so mortified in my life. I wanted my kids to feel proud of me, now all they see is a sick mum who can no longer give them pocket money, take them to nice places or even feed them. I now have to get them to look after me, clean up the house, cook meals, do the shopping as i'm often too tired to help and for no recompense. No wonder they'd rather live somewhere else nowadays and no wonder my daughter self harms. The strain this ugly illness is putting on us is shocking and no one is willing to help us out.

You people are wealthy, you get paid very high salaries and never have to consider just how tough it is for the REAL sick people in Edinburgh. All you ever think about is the Junkies or Alcoholics or the people who are at it who you need to penalize for claiming benefits yet you end up also penalizing the people who really do need the help and support through no fault of their own. Hell if I were an illegal immigrant I'd be entitled to much more than I am currently getting yet I'm British born and bred, I had a horrid childhood of various abuses yet I used that as my motivation of moving away, moving on and giving my children a much better life than I ever EVER had.

Do you know it took me 5 months to get a permanent wheelchair from the NHS. I had to borrow one from the British Red Cross and am mortified that I had to hand it back this week unable to donate anything to them because all my moneys been cut. These people went out their way to help me with a vital piece of kit yet I can't thank them for that.

Not to mention the Wheelchair I did get is a manual one which my daughter and stepmum are finding it difficult to push. Ideally given my circumstances I would have been better getting an electric wheelchair yet to get that you need to get the full DLA, again another vicious and long drawn out circle. Yet it takes months for the specialist appointment and even then one appointment is never enough, often sufferers take years to fully diagnose so what then?

Why do the government make it so hard to get the much needed help that people like my family really need?

Do you know of anywhere I can get the vital help and support we need? I've exhausted every avenue I and Google can think of.

Why isn't there a seconds scheme for disability aids? Why does everything have to be binned after their first owner, surely if you had a seconds scheme many more people could get the use out of vital equipment and not have to wait so long.
You know through the goodness and kindness of the Edmesh group, an ME support group I've gained more support and advice from them than I have from anyone in the government. I joined their facebook group and within minutes finally felt listened to and supported even though all they could do was offer advice, just the fact that they are in the same boat was enough.

Through the kindness of the group a fellow sufferer donated their old Mobility Scooter which was surplus to requirements to help take the strain off the kids having to push me everywhere. This was a massive help. I can finally go to my local supermarket independently however due to Lothian bus regulations I cannot travel by bus on my scooter even though it is the boot scooter version and not the huge pavement variety therefore the furthest I can go is Cameron Toll as long as its a good day, if its wet I have to take a taxi costing almost £10 or stay in and feel like I'm locked up in a Jail Cell! Please tell me how I am meant to still do vital shopping trips with the kids on £71 if a taxi there and back is £20? Surely it would be more cost effective to look at a persons circumstances and give them mobility aids which would make life easier rather than the bog standard in the hope its 'ok'

I don't even vote anymore because what's the point? You ALL made this predicament happen yet none of you are willing to change things for the better. There are over 200 Edinburgh Constituents in the Edmesh community on Facebook and very little of them get DLA for their ME/CFS despite suffering almost daily with debilitating symptoms. Some like myself are being told by work that we 'may have to retire due to ill health' I'm 33 years old!! Yet to the DWP our condition is 'fake' or 'not recognized by a test so cannot be given support'. Really??

Imagine if I were your daughter! How would you feel knowing that I'm so ill most days and no one is able to help, that I cannot feed my children because I cannot work due to no fault of my own. How would you feel as my daughter or son? Having some days to help me to the toilet or at my worst Help perch over the bed and pee into a bucket because just walking to the toilet is too much. Imagine how I feel knowing that I'm having to get that help from my kids because there really is no one else nearby who is able to help!

Actually when you think about it the Government is discriminating me because my disability is ensuring I cannot work!! And there was me thinking the Government was against Disability Discrimination!!

Its taken me all day to write this email due to tiredness, being upset and frustration that I'm now in this position through no fault of my own. So I guess all that leaves me to say is do you understand how tough life is for me and even others like me?

Can you help make things better?

Can you point me in the direction of anywhere that can help?
WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM HEATHER CUTHBERT

I have been ill for 25 years and was in receipt of Incapacity Benefit until it was changed to Employment And Support Allowance. I was called to Cadogan Street on Friday 24th May 2013 and was interviewed and examined by an Atos Doctor who deemed me fit for work when clearly I am not and gave me no points at all this meant my benefit was to be removed however I took them to a Tribunal on 8/10/2014 at HM Courts & Tribunals Service, Wellington House, Glasgow where the Judge awarded my appeal under Regulation 29 of the ESA Regulations 2008 applied but could not overturn the no points decision by Atos I was therefore entitled to Employment and Support Allowance with the work related activity component.

I have received a letter from the DWP advising me that my benefit will completely cease from 11th July 2014 because I have reached the maximum of 365 days that you get contribution cased Employment and Support Allowance the letter is dated 7th February 2014 and if I want to ask them to look at the decision again I have got to reply by 7th March 2014. I feel that I have been wrongly treated by Atos and the DWP and my Doctors who refused to give me a Medical letter but filled in a form online with the minimal details I obtained Medical Evidence myself and sent this to the Tribunal.

I am ill, I am in receipt of an Industrial Disease Pension and am 20% disabled due to an Impaired Bowel and I would not be able to hold down a job surely Regulation 29 should still stand as my health has not improved I am fed up always having to take them to Tribunals.
WELFARE REFORM COMMITTEE
YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM ELIZABETH DONALDSON

I am sending this e-mail, not as an organisation, but as an individual working full time in a good job, but supporting a family member to exist.

My brother receives no benefits due to the changes in the benefits system. He did receive ESA up to the point when he had to go for medical assessment with ATOS who declined his claim. This assessment was conducted by a physiotherapist not a qualified doctor.

His benefit was stopped completely on 5th November 2013 since when I have paid all his bills and helped him with money for food.

He filled in a form for an appeal at that time and is now waiting for another assessment.

At the moment he is going round in circles, being told by one department that he can get money and by another department that he isn’t entitled to any money.

His health is being affected even more with all the stress involved with this, and I feel that although I am nearing retirement age, I will have to keep working to support him. Luckily the house he lives in is owned outright by the two of us otherwise he would be facing eviction.

He has been told by individuals at the DWP that if he is so poor he should sell the house which I think is utterly contemptible and would render him homeless.

I find it difficult to reconcile the fact that although the national government can send aid to every country on the planet, they can leave residents of this country without any money whatsoever.
WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM ANITA DUFFY

I was diagnosed with Multiple Sclerosis in December 1999, and managed to work full time as a Staff Nurse until April 2006. In the latter years, I had a lot of sick time and fought tooth and nail to keep my job, because I loved it so much, but it became quite apparent that I had to give it up, and so I was ill health retired from nursing altogether. Coming to terms with my diagnoses and the limitations it put on my life was very difficult for me. It took several years to settle into this new life of unemployment and benefits. However, I could then focus on my health and keeping myself at my optimum since the stress and pressures of work were lifted.

This was all turned upside down when I was sent an application for the new ESA benefit which was to replace my previous Incapacity Benefit. This is a huge document, which asked me questions which I felt didn’t reflect my circumstances. I was asked to fill it in as my worst days would be. I am a positive person and like to focus on the good things that I do, and not the things I can’t do. The bad incidents (relapses and varying daily symptoms) in my life have literally been blanked out of my mind. This is how I cope with my illness, and yet I was being asked to revisit these dark times. Obviously this was very upsetting. The forms were exhausting to complete and had to be filled in over many days. I had no idea if I was doing this correctly or not, and whether I remembered everything. It was so vague and confusing and didn’t allow for the variability and unpredictability of Multiple Sclerosis either. I was absolutely fatigued and distressed when I finally finished.

I was subsequently called for an assessment by ATOS. I was worried now. Not about the actual interview, but about getting to the place, how it was laid out, where would the toilets be, what if I fell, or had an accident. I also worried about how tired I would be, and would I make a fool of myself trying to explain things and not find the right words or get confused…..oh, so many things…and more! My Mother had to come with me to help with all of this. It helped a bit. The interview itself was fine, but I still felt anxious, at the time. I answered as best I could with Mum filling in as needed. I left feeling relieved. A letter soon followed placing me in the Work-Related Group and I understood it to mean I had passed the assessment. (I did not fully understand the implications).

At Job Centre Plus, which also wasn’t easy for me to get to, I became more confused. I was to attend Life Skills as a requirement, and they would help me get a job, IF I wanted to work. I thought this was very weird. Who is going to employ me? However I went, all the same. The woman there, very quickly realised that the only way I could work is if I worked for myself, and so promised to send me on some courses to facilitate this. I never received this information, so I assumed this was all a waste of time, and so did she. I had no real idea why I had been sent there, in the first place.

My money remained the same as when I was on Incapacity Benefit, and so I felt this was the end of my processing for ESA. However, my friends at The MS Therapy Centre were now all being assessed too. They were talking about 2 groups, and I didn’t know what they were referring to. I then got a letter from Job Centre Plus
telling me my money will be stopping in December as that was the year up on my benefit entitlement. I couldn’t believe it! What do I do now? I knew I couldn’t work, but I couldn’t live without this small amount of money. I couldn’t sleep; I became quite agitated and emotional. I didn’t know where to turn. My Mother suggested Citizens Advice Bureau, and so I made an appointment, with her support. Almost immediately, they told me I should appeal and were confident I would win the appeal. How could they be so sure? At that point, it was all taken out of my hands and the wheels were set in motion. I couldn’t believe it was this easy. Up to now, I was like a deer caught in a car’s headlights, and now I was being caught up in this whirlwind of (apparent) certainty that I would get into the right group now. I couldn’t help but be stressed, especially when the payments stopped on 7th December 2012. For 2 months we struggled financially and then I got the most confusing letter from Job Centre Plus. Like all the other letters, it was confusing gobbledegook. I had to get others to read it to understand that I was now in The Support Group of ESA. CAB were right! Amazing! I was stunned, but tremendously relieved too. A huge weight had been lifted.

On reflection, I cannot believe how lost I felt over those 5 or 6 months. What little control I had left in my life, had been taken away. I am fairly new to the Benefit system, and my naivety did me no favours at all. Despite having a good support network of friends and family, I hit an all-time low in my life. There’s no doubt about it. It was like my world had come to an end. I think I am quite a level-headed, well-educated, rational person in normal life, and yet I was made to feel hopeless, demoralised and worthless. How do more vulnerable people cope with this intolerable strain on top of their illness?

I don’t understand why we have to prove, time and time again, how awful our lives are? Isn’t it obvious? It’s not my choice to have this illness and to lose a job I loved, and I’m NEVER going to get better. That’s the nature of the disease I have, and yet The Government and its various departments insist we tell them over and over again, in detail, on an annual basis, what we can’t do. What a waste of time and energy for all, not to mention taxpayer’s money, because someone’s getting paid to do this!

Surely, the fact that Multiple Sclerosis is a progressive Neurological disease is all the evidence required. The conclusive evidence is on repeated MRI scans and continual assessments by expert medical professionals. That some people can work with this illness in the early stages (as I did) is undeniable but if you’ve been ill health retired out of your job already, surely it’s obvious that your diseases is progressing and the likelihood of working again is remote. I feel there is a lack of understanding, no compassion, and that we are being repeatedly punished for being ill. Now we are going to have to do all again with the new PIP replacing DLA. It beggars belief that we live in a progressive civilized society!
WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM CHRISTINE DUNCAN

In March 2009 (5 years ago) I took ill, with what was much later diagnosed as cervical myelitis, a neurological disorder for which there is currently no treatment or cure. My life literally changed overnight due to the debilitating nature of my illness and resulting disability. I also have chronic fatigue which often runs alongside a myelitis (or indeed any other chronic illness) diagnosis.

I was in employment at the onset of my illness however I was declared unfit for work on 17th March 2009 by my GP. This was the beginning of a period of sick leave which would last for almost 2 years. In February 2011 my contract was terminated by my employer on the grounds of incapacity.

In October 2009 I was advised by my employer that I was eligible to apply for Employment Support Allowance, a benefit I had never heard of let alone have any knowledge or experience of. I contacted the Department of Work and Pensions and made my application by telephone. At that point I provided them with all the information required for my claim and trusted them to get it right by awarding me the correct benefit relating to my circumstances. I was advised that I would receive Contribution Based Employment and Support Allowance.

In the years that followed I attended 2 medicals that were conducted by ATOS. My understanding of the outcome of these medicals was that I had been deemed unfit to work and that I would continue to receive ESA.

In April 2012 I received a letter from the DWP to inform me that my ESA was changing from Contribution Based to Income Related.

Not long after this, because of a negative experience a friend was having in relation to her ESA, I was first made aware of the Work Related Activity Group, the Support Group and the meanings behind both with regards to ESA. Not having a clue which group I was in I telephoned the DWP to find out. I was informed I was in the Work Related Activity Group. At this point I said I should be in the Support Group as I was not fit for work both physically and cognitively. I was advised that my period to appeal this had exceeded and so there was nothing I could do about it. Apparently information re all this had been included in the correspondence sent to me by the DWP however due to the cognitive difficulties I experience, as a result of my illness and its symptoms, written information is of no use to me.

In August 2012 I received a letter informing me that I was being investigated for benefit fraud as I had not informed the Department of Work and Pensions that I was living with my partner. I was to attend an interview on 23/08/12 which could lead to me being charged and prosecuted. In amongst the panic, worry, stress and sheer terror caused by this letter there was also extreme confusion as to how such an allegation could arise. I had informed the DWP that I was living with my partner when I initially made my claim in October 2009. At that point I had provided them with his full name, date of birth and National Insurance Number. Also every time I had cause to phone the DWP they would take me through security. The security question
always being, “What is your marital status?” to which I would always reply, “Living with my partner”. Their reply would then be, “Correct. You have successfully completed security”. But now they were telling me they did not know I had a partner who I was living with??!! I attended the meeting on 23rd August armed with extensive information to show that I had informed them that I lived with my partner. The outcome of this meeting, as advised in a letter several weeks later, was they were satisfied benefit fraud had not been committed.

However during this meeting on 23rd August 2012 it was explained to me I was currently in receipt of a benefit I was not entitled to i.e. Income Related Employment and Support Allowance. I then asked what benefit I should be receiving. The answer being none, due to the fact I have a partner who is in employment. Having worked since the age of 15, having paid tax and national insurance for 20 plus years I was now in a situation where it was my partner’s responsibility to support and provide for me. A partner who had only come into my life 6 months prior to the onset of my illness and who had not been by my side while I was working and paying tax and national insurance. I was astounded and distressed to find myself in such an incredible situation.

As a result of me receiving a benefit I was not entitled to we had incurred a gross overpayment of our Working Family Tax Credits. I disputed that we should not be liable for this overpayment as it had occurred through a clerical error made by the Department of Work and Pensions but I was told we would have to pay back the overpayment. This amounted to thousands of pounds.

As a family we could not afford for me not to be in receipt of any income. We had found ourselves to be in increasing financial difficulty as a result of me not being able to work and were desperately trying to get back on our feet. Now we had even less money coming in to our household we could not meet our monthly financial commitments. I had no option but to try to find a job and return to work despite the fact that I am ill and disabled. The difficulties of applying for jobs, attending interviews and being able to meet the job requirements were compounded due to the fact I have 2 chronic illnesses and a disability.

I secured a temporary position with a national company to cover their busy Christmas period with the possibility of it becoming permanent at a later stage. Despite the reasonable adjustments they made for me I struggled with the job specifications due to my physical and cognitive restrictions and limitations. There were some duties specific to my role that I could not perform at all. Contrary to what I had been led to believe, I was not offered a permanent position with them once my 12 weeks contract expired.

I then secured another job with yet another national company. 5 weeks in to this post, on 1st March 2013, I experienced a breach of the Equality Act which resulted in me raising a grievance with the company. I had to go through their internal grievance procedure which took in excess of 3 months and was only resolved to my satisfaction after I had lodged my case with the Employment Tribunal Service. My G.P declared me unfit for work during the grievance process until my employment with this company ceased on 21st June 2013.

I now felt I had clarification that I was not fit to work and I reapplied for Employment and Support Allowance. I received a letter to say that I would receive Contribution
Based ESA from 22nd June 2013 however no payments appeared in my bank account. When I telephoned the DWP to ask when I was to receive my first payment I was told I was not eligible for the benefit on the grounds I had not paid enough national insurance contributions in the required years - despite the fact that during the required years I was either in receipt of ESA and national insurance contributions were being paid through this on my behalf or working and paying national insurance contributions through my employer! I stated I had a letter informing me I was entitled to ESA but was told that was a mistake.

I telephoned Citizen’s Advice and they advised me to check with the National Insurance Office re my contributions for the dates in question… which I did… and was advised I had paid full national insurance contributions for the relevant years. I telephoned the DWP to explain this to them and to say I therefore must be entitled to Contribution Based ESA only to be told it was a different type of national insurance contributions that I had paid in these years and they were not the right ones required for me to receive Contribution Based ESA.

I was incensed with the unjustness of this situation. Here I was, a British national who had worked all my adult life, until rendered incapacitated by a neurological disorder and resulting disability, and who had paid British Tax and National Insurance being told I was entitled to nothing from the benefit system. Yet people who never worked or had been long term unemployed or who had not long resided in Britain were in receipt of various government benefits. I telephoned my local MP to complain about this and he contacted the DWP on my behalf. As a result I received a telephone call in July 2013 to advise me that because my MP had gotten involved they had relooked at my case manually and discovered I had paid the correct national insurance contributions for the years in question and therefore I was entitled to Contribution Based ESA and that my payments would be backdated to 22/06/13.

Had I not contacted my local MP and had he not acted on my behalf I would have continued to not receive a benefit that I was eligible for and entitled to. I am gravely concerned about this. It begs the question how many people are accepting wrong information and explanations given out by the Department of Work and Pensions in relation to ESA and other benefits and are therefore not receiving money they are entitled to. I could so easily have been one of those people!

In the autumn of 2013 I received another phone call from the DWP. This time to inform me that due to the answers I had provided in the medical questionnaire I had submitted in relation to my ESA application I was being put into the Support Group for 2 years and during this time it would not be necessary for me to submit sick lines or attend medicals.

Finally, 4 and a half years after the onset of my neurological disorder, I was where I should be in relation to Employment and Support Allowance. This, however, is only until 2015 when there is the possibility the worry, stress, mayhem, mistakes and financial hardship may start all over again.

During the time I was forced back in to employment as a result of my benefit having been stopped I was made to feel inadequate. The focus was on what I could not do and I was treated with intolerance from colleagues. This was particularly applicable to the second post I secured and where the Equality Act was breached. I am often clumsy due to my physical restrictions. This was met with sighs of impatience. My
cognitive functioning has been affected by my neurological disorder and I am unable to process, retain or remember information or instructions. I was repeatedly told that I had been told that or shown it already. I found it to be demoralising, my confidence was greatly knocked and my symptoms were more pronounced due to the physical and mental stress I was experiencing.

For me it has been a litany of unacceptable experiences in relation to applying for and being in receipt of Employment and Support Allowance. At a life changing time when I should have been concentrating on accepting what had happened to me, exploring more about my condition and learning how to manage my symptoms I was distracted by the stress and worry caused by the benefit system and the mine field I found it to be. It had adverse effects on my symptoms due to the relentless stress, worry and problems inflicted upon me. The physical input, mental effort and time consumed during this saga prevented me from being able to pace myself which is the one thing I benefit from.

It is wholly unsatisfactory that people with incurable, and often progressive illnesses, and permanent disabilities are being subjected to the inadequate benefit system that exists in Britain today.
WELFARE REFORM COMMITTEE
YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM ENABLE SCOTLAND

Welfare Reform Committee
January 2014

Your say Call for evidence on the impact of welfare reform on people with long term disabilities

ENABLE Scotland is pleased to be able to facilitate the engagement of our members in the Your Say call for evidence on the impact of welfare reform on people who have long term conditions and disabilities. We have pleasure in submitting a video diary to the Welfare Reform Committee which captures the concerns of our members, in their own words. Members and clerks can access the film here:

About ENABLE Scotland: ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with around 4000 members in 45 local branches and via individual membership. Around a third of our members have a learning disability.

People who have a learning disability have a significant, lifelong condition that started before adulthood. This condition will affect the way that the person’s brain develops which means they may need help to: understand information; learn skills; and cope independently.

It is the experience of ENABLE Scotland that people with a learning disability are impacted disproportionately by welfare reform as they are more likely to be unemployed than the general population and are therefore more likely to require the assistance of the welfare state. Of those who are in paid employment, many still retain benefit entitlement by virtue of Disability Living Allowance, Tax Credits and Housing and Council Tax Benefit.

About this submission: At our AGM in November 2013 our members were given a presentation to update them on the progress of welfare reform and what these changes might mean for them now and in the future. We explained that the Scottish Parliament’s Welfare Reform Committee was interested in hearing their views on this.

Following this presentation, we gave our members the opportunity to take part in a video diary to tell the Scottish Parliament how they felt about the changes to the benefit system.

We are therefore pleased to submit this video diary to inform the Your Say process, and we hope that this provides a valuable insight for the committee into the worries and problems faced by people with a learning disability in Scotland as a result of the welfare reform agenda.
ENABLE Scotland are happy to work with the welfare Reform Committee on any future issues where our input might be of assistance, and we look forward to the outcome of the Your Say call for evidence with interest.
Dear Michael and members of the Committee,

Thank you for a copy of the letters from Deputy First Minister Nicola Sturgeon and Minister of State for Disabled People Mike Penning in response to our open letter from DPO’s and Allies. As you know, we were prompted to write to you due to our serious and numerous concerns about the impact of welfare reform on disabled people’s human rights.

Since our letter to you in June of this year, the situation for disabled people has deteriorated even further. This is due to both the impact of the current welfare reform agenda which is being implemented to devastating effect as we speak, and also further measures which have been proposed by the UK Government which will make life even more intolerable for tens of thousands of disabled people in Scotland.

The raft of measures being imposed on disabled people have already rolled back decades of progress in relation to disabled people’s civil and legal rights to Independent Living. In addition, the DWP will introduce further measures which will cause thousands more disabled people to be imprisoned in their homes, homes which are no longer secure or affordable, thanks to the bedroom tax.

With the introduction of Personal Independence Payments, the DWP is slashing the distance someone can safely walk before qualifying from 50 metres to 20 metres. This appears to have no logical basis other than cost savings by changing the goalposts i.e. “You’re no longer disabled so you won’t need that money”.

The 50 metre benchmark is widely used as a measure of significant mobility impairment, including for blue parking badges and in official guidance on creating accessible built environment, such as how close parking spaces have to be to buildings.

Many people, who can walk a little, 50 metres rather than 20 metres, will lose essential vehicles, including adapted cars or specially converted wheelchair accessible vehicles. Those who use their higher rate of DLA to hire / purchase a specialist powered wheelchair scooter will in effect “lose their legs”, their independence and the means to travel outside their home with some dignity.

People who fail to qualify for the new mobility component may lose their independent mobility and are very likely to experience greater social isolation. Depriving disabled people of independent mobility will increase costs elsewhere due to the knock on effects in health and social care services: this breaches human rights, including the right to social participation which is part of Independent Living.
Many people rely on their higher rate DLA to pay for adaptations to their home or mobility equipment and often have loans based on DLA payments previously awarded as “for life” or “indefinitely”. Those people awarded DLA “for life” or “indefinitely” are disabled people with significant levels of impairment and frequently those with lifelong, progressive conditions. It is unfair and unjust for such people to be subjected to further and on-going assessments.

This change is going to hit hard on disabled people in Scotland. Using the DWPs own projections:

- 80,000 working age disabled people in Scotland will lose either some or all of their mobility allowance they would otherwise have been entitled to.
- 74,000 disabled Scots who would have otherwise been entitled to Lower Rate Care will no longer receive it because it will no longer exist. The subsequent loss to disabled people will be at least £90 million per year.
- 47,000 disabled Scots will lose their higher/enhanced rate mobility allowance. The subsequent loss of income to disabled people will amount to at least £135 million per year.
- 34,000 disabled Scots will lose standard rate mobility allowance. The subsequent loss of income to disabled people will be at least £37 million per year.
- 30,000 fewer disabled Scots will receive Standard Daily Living/Middle Rate Care. The subsequent loss of income to disabled people will be at least £83.4 million per year.
- 16,000 disabled Scots will lose their Motability cars and scooters.
- The total loss in income to disabled people in Scotland simply from the change from DLA to PIP will be at least £336 million per year.

I note that the Deputy First Minister and the Scottish Government are of the opinion that:

“Meanwhile, until such time as the Scottish Parliament can make its own decisions about welfare matters, we will continue to press the UK Government that the most vulnerable people in our society must be protected.”

We welcome this commitment and would urge you to go further to address the complexity and scale of the sustained and regressive attacks on disabled people. Disabled people need reassurance and are suffering now and into the future. Unfortunately, we are not confident in the capacity of the UK Government to protect the most vulnerable in society. The Minister of State for Disabled People in his letter stated that:

“There are a lot of misleading stories about the impact of our welfare reforms on disabled people… the UK continues to be a world-leader in the rights for disabled people.”

With over 2000 disabled members, almost all of whom are affected by the reforms, GDA is concerned that that Minister of State for Disabled People is not aware of the
overwhelming evidence available about impact including the regression of rights. Whilst the UK may at one point have been close to a world-leader in disabled people’s rights, as the Chief Executive of one of the largest Disabled Peoples Organisations in the UK, I can assure both you and the Minister for Disabled People that this is now far from the truth. I am certain that this will emerge when the United Kingdom comes before the United Nations Human Rights Council next year.

Thanks again for writing to the Deputy First Minister and the Minister of State for Disabled People. At this time, I would like to repeat the call for the Welfare Reform Committee to take the following actions, with even greater urgency:

- Conduct an urgent review of how the impact of welfare reform violates the human rights of disabled people
- Urge the Scottish Government to adopt measures to protect the human rights of disabled people
- Conduct a full human rights impact assessment, including on Independent Living, on legislation which is brought before the Committee aiming to mitigate the impact of welfare reform
- Recommend that the Disabled People’s Movement is included and engaged with across all areas of government to ensure actions to mitigate the impact of welfare reform and cuts to services are being actively considered at every level.

I am grateful to the Welfare Reform Committee for conducting the „Your Say” events, and with this letter I enclose stories from dozens of disabled Scots and those with long term conditions, which demonstrate just how serious this situation is, and how much more needs to be done.

The following are quotes from members of Glasgow Disability Alliance who are disabled and have long term conditions. Each of these is to be considered as an individual response to ‘Your Say.’
**Lillian   Age 65**

People think we're just scroungers and we want money for nothing, which is not true. We want to get out in the community, and work and I myself do volunteer work because I want to give something back to the community.

If I didn't get DLA, I would be housebound, because I'm 20 minutes walk from the nearest bus-stop and I'm not very good at walking anyway, and even if I could get to the bus-stop, I use a walking frame which is not easy to get on an ordinary bus.

I've very concerned about the welfare reform, for me and thousands of people like me, because if we lose these benefits, we are absolutely stuck.

People don't understand that we don't want to be disabled, it's a fact of life and it can happen to anyone. You can have an accident, one day you could be perfectly fine, and like Christopher Reeves, the actor, he fell off a horse, broke his neck and he was paralysed for the rest of his life. It can happen to you, just as easily as it happened to me.

So, I would like to say, think about what you're doing to all disabled people. Think about how you're taking away their lifeline, and that's exactly what you would be doing."

**Kirsty B   Age 33**

Something that's huge for me is the changeover from DLA to PIP. I've been getting DLA for years and a lifetime award because I've got cerebral palsy and it's a lifetime condition, it doesn't get better, it's forever so you're either at the stage you're at or you could get worse if there are associated conditions. So, this idea of going on to PIP and being constantly assessed for something that isn't going to change to my mind is a bit of a concern because you're having to then pay for people to assess you every so many months or every so many years so it'll cost the government a hell of a lot of money just to facilitate that.

It's something that's actually happened to me before where I was housebound for three years at the age of 27. Completely isolated, couldn't get anywhere and as a result sunk into a really bad depression and was suicidal over it and I don't want to go back there again because it's something that effects your ability to get back to work and if you're in that kind of place and trying to rehabilitate yourself and get back out there again it's too hard.

So, it is something I'm really really nervous about.

And for me personally it's that if I go on to PIP, and if the criteria changes I could lose my mobility car, which for me is an absolute life line, it's my legs as I keep telling my family, you know if I lose my car I lose my legs, I lose my independence, my dignity, and I lose the control over the choices I want to make in my own life rather than having to depend on everybody else 24/7.
David       Age 62

I've had a stroke which obviously affects my ability to speak. You can have six different types of strokes and with that subdivisions of that. How can you understand, I mean how can that doctor listen to me and understand what form of stroke I took, a consultant would do that, but Atos won't deal with any consultants they won't deal with your doctors, and that's just appalling.

The car goes, the house goes, what else does this government want from me?

Marianne    Age 43

I think it's important to remember that welfare reform affects disabled people who are also working. I get disability living allowance and because my condition is active and progressive and lifelong, my award was given as a for life award which was fantastic, and that meant I could use that award to buy a car which was suitable for me to drive, it also meant that I could buy myself a wheel chair, and it also meant that I could use that money to pay for adaptations to the house that I needed, that I don't qualify for any other type of support for, due to the fact that I'm working.

So my DLA, again because it's a life award, meant that I could get a loan for my adaptation, so I can get a bathroom that meets my needs but the important thing for me is, I can't use public transport and my car means I can get myself to work, use my car within work, and my DLA award also means I can supplement the small amount of money I get from Access to Work to employ personal assistants to help me, both at home and in my workplace.

If I didn't have my DLA - and I'm really quite concerned about the fact it might be taken away from me - it means that I might have to give up my car, which means I wouldn't be able to get to work, so I may have to give up my job and then two people who I employ to help me as personal assistants also lose their job, so all three of us could actually lose our jobs because of the fact someone's decided that people like me don't need that sort of support.

So, the huge knock-on effect of not having disability living allowance, means that disabled people, including people like myself, end up not being able to work, not being able to think about working, or volunteering, or contributing to their communities and end up just stuck at home, with nothing to do, and bored, and actually cost the state much more for example because not only do they lose social participation, but they're likely to become depressed, more ill, more in need of NHS services.

Kirsty J     Age 24

If my money is cut or stopped, my mum or dad can't give me any money. I don't want them to, because I want to be the same as everybody else, a regular young person. Myself and my other friends are concerned with the cuts because it'll effect our future, and our daily lives.
Gary  Age 25

My personal situation relates to the bedroom tax, due to the fact that the government is wanting me to pay for an extra bedroom that first of all, I never asked for; I never asked for it, that was the house that was allocated to me, because it was the only accessible house available at the time.

To be honest, having to pay that extra cost from my benefits, it's really going to have quite an impact on my situation.

These changes would really affect me substantially, it would mean less integration with my peers, and less integration with my family.

I think that all people in society should be able to have and enjoy. Just because we have a different way of doing things to other people doesn't mean we should be at a disadvantage for the basic things other people in society take for granted.

Surinder  Age 38

If I lose my DLA, which is going to be devastating, and move over to PIP - which is Personal Independence Payment - one of the parts I'm going to lose is the mobility component which pays for my vehicle and allows me to socialise and integrate with society, and if that's going to be severed, which it looks as if it is going to be, then I am completely and utterly isolated, I'm imprisoned in my own home. I'm not going to be able to visit my relatives and friends and it's going to have a detrimental effect on my health and well-being, which I'm really concerned about.
We asked our membership of over 2,000 disabled people three key questions about the impact of the change from DLA to PIP.

1. Do you get DLA mobility and what does it mean to you?
2. What would life be like without it?
3. How will these changes affect disabled people in general?

These are a selection of disabled people’s comments. They have been anonymised to protect the identity of our members and to ensure there are no repercussions from the DWP due to people speaking out:

1. Do you get DLA mobility and what does it mean to you?
   - “Yes, it means freedom, independence, choice, control, being involved in the community, social involvement.”
   - “Yes it means I can go where I want when I want with who I want. I use it to drive.”
   - “I can only walk on very flat ground. Testing in a nice indoor office does not take account of the fact that most ground outside is uneven, with difficult steps and kerbs. A 3 in kerb can feel like Everest to me. The new limit of 20 metres is unfair and unrealistic.”
   - “I have left spastic hemiplegia which leaves me unbalanced.”
   - “Couldn’t cope without it – would not get out at all.”
   - “Yes, it means that I can get to and from hospital appointments, interviews, to go shopping etc. It also means that I can go out socialising with my family and friends.”
   - “Yes, it greatly increases the quality of my life, by enabling me to participate and contribute in my community. It gives me my independence, freedom and gives me greater control of my life.”
   - “I have an accessible vehicle – if I gave this up it would be I would have to take taxis everywhere and I would not be able to afford that.”
   - “Yes, I get DLA at high rate mobility. DLA means that I can go out and about, meet friends and live an independent life even though I need support.”
   - “Allows me to be independent – go out and get shopping.”
   - “The difference between independence and relying on others to help.”
   - “Helps me get to places I can’t otherwise go.”
   - “DLA and Motability it means I get taken out more and am able to work.”
   - “If I didn’t get it I would be stuck in the house.”
   - “Gives me my independence and it helps me to run a car and day to day expenses of being a disabled person.”
   - “It means I can get around safely from A to B because I have different leg lengths I have a built up shoe and leg brace. Without it I can’t walk out or indoors without my support.”
   - “Yes helps me financially, enables me to get out and about and keeps me well.”
   - “Yes I do. It is a life line to me the only way I get out and about is by taxi.”
• “My mum gets it for me as she is my carer. It means my mum has a mobility car which helps me around and gives me independence.”
• “Yes I get DLA mobility and have a Motability car. Having a car gives me the freedom and ability and ease to get to appointments, do shopping and be able to get out and meet friends.”
• It means I can go out, go to volunteer, try things and keep connected. This makes me more able to cope when things go wrong
• “Yes I get DLA and Mobility means a lot as it means I can get out more.”
• “Yes, I get the higher rate and it means I get to drive my own Motability car. It’s my legs, my life, my independence, my choice.”
• “I need special footwear that I have to buy myself and I rely on my DLA to pay for these – it’s not always just about cars, it is about the basics – mobility is vital to independence. I would literally be barefoot if I lost my DLA.”
• “Higher rate DLA is a passport benefit – for blue badges, bus pass, support for carers, memberships to different clubs / services, reduced prices for services, even things like being able to get free carers tickets for the cinema, etc. There is so much to lose that we rely on.”

2 What would life be like without it?

• “Isolation, poverty, depressions, suicide, Prozac prescriptions. Unable to contribute to voluntary positions. Local economy suffers as we are unable to go out. Church funds deteriorate and higher costs on social services.”
• “Wouldn’t be able to travel to work, it would have a big effect on socialising. If I ever wanted to go to college this would play a big part.”
• “I would not be able to get out on my own because I could not afford it so I would be isolated and depressed.”
• “A nightmare, because I would not have as much independence to travel around with my mum and dad.”
• “I would be socially isolated and unable to do so many everyday things that non-disabled people take for granted. I would be unable to participate in volunteering and lose a lot of social contact with family and friends.”
• “It would be difficult to get out and would be boring basically because it helps me get out and to be able to try and get out the house as it is difficult sometimes if I am in pain.”
• “I would be isolated; I would be unable to be spontaneous in my life.”
• “I would lose networks of confidence and support.”
• “I would be stuck in the house relying on family members with cars or even taxis which would cost quite a lot and there is no taxi card scheme to help.”
• “It would make my health deteriorate as I wouldn’t be able to go out to a flat surface place such as a shopping centre where I am able to walk then sit at a table.
• “Life without DLA would leave me socially isolated, leave me housebound, staring at four walls. I would be financially worse off and leave me back where I was 15 years ago, unhappy and unable to see my friends.”
“I would be housebound.”
“My ability to cope with things would be eroded. My world would become smaller and narrower until there was nothing left”
“Stuck in the house, would need to give up my car. Poverty stricken, less independent, unable to work.”
“My depression would get worse.”
“Reduction in level of life standards and lifestyle – gives me opportunities to get out and about.”
“It would be terrible.”
“I will have to stop working.”
“I use my DLA to pay for my car, which enables me to stay in work. Without my DLA I could not stay in my job as I can’t use public transport or taxis.”
“I wouldn’t be able to hold down a job, go to college, meet up with my friends and do all the normal things that able bodied people take for granted. I was housebound, isolated and suicidal without it. Public transport is really poor. Glasgow pavements and roads are a mess and really dangerous so having my own car is my only option to live a normal life. I have a walking stick; I can’t carry a week’s shopping home on a bus and can’t afford constant taxis.”
“I can walk a bit but it causes me great pain and it takes me ages to recover afterwards. Without my DLA, I would lose my car. Ironically, losing DLA would mean I would have to go back to using a wheelchair all the time to get out and about, whereas now I can walk about a bit as I have my car to get me from A to B which saves me pain and conserves energy.”

3  How will these changes affect disabled people in general?

“The walking test is almost always done on a flat, smooth surface. This is not the reality. Try walking outside on the uneven pavements and the two inch kerbs to overcome. It is the equivalent of conquering mount Everest and hoping not to fall.”
“Regression.”
“They will become disempowered, unable to work, volunteer and to participate in society in general. It is a false economy as it will put pressure on social care and health budgets. Disabled people will become prisoners in their own homes.”
“Very unhappy, depressed, very isolated, stuck in the house staring at four walls.”
“Less people qualifying is a retrograde step. Ironically more demands on other services.”
“There would be more trips to the GPs.”
“I think in general it would cause a lot of other problems such as a higher number of deaths due to not getting out exercising, people would become lonely, stressed and the number of unemployed people will get higher as people wouldn’t be able to go to interviews.”
“More people housebound, more reliant on social services and the NHS. Increases in mental health problems. Peoples physical conditions getting worse because they can’t get out without support.”
• “This change will mean more disabled people will be stranded in their homes – this has an effect on people’s mental health and wellbeing.”

• “They would be isolated, less social interaction, less independent and many people would have to give up working.”

• “It will affect their wellbeing and cause more mental health problems. Stop people from working, taking part in social activities it will cause a lot more exclusion.”

• “I think the suicide rate amongst disabled people would increase and more disabled people would be imprisoned in their own homes and feel neglected from society.”

• “It will cause depression, not being able to travel about or education. It could lead to not having a career. It might mean less independent living and more reliant on parents.”

• “Makes people depressed and angry as some people need it just to live.”

• “My level of DLA was reduced even though I clearly need assistance on a daily basis. On appeal I felt like a criminal who was prejudged as a cheat.”

• “Disabled people will become reclusive and lonely. Their health will be affected and it would cost more money in the long run. Disabled people wouldn’t be able to live independently and therefore will rely on others which in turn causes the disabled person to lose their dignity, self-esteem and control of their own lives.”

Disabled people will lose the human right to have connections with others- to socialise – even if it’s just going to the shops; to be part of our communities and to enjoy our families and friends if we’re lucky enough to have them; to work or volunteer or to access learning and education; to take part in civic duties or even political life- these are all enshrined in human rights and the additional treaty- the UNCRDP- because it is acknowledged that disabled people struggle to realise these rights at ordinary times. But taking away the very lifeline which kept many of us connected will result in a further loss of rights. This is a human rights issue.
I was diagnosed with MS in Aug 2010 having been ill for a year (secondary progressive MS) seems I have had MS since at least 1975.

I attended an Atos assessment in Oct 2010 and was declared fit for work.

I appealed lost the appeal so I made a new claim.

I again attended an Atos assessment in Nov 2011, again found fit to work.

I then appealed but also attended the WRAG at my local DWP and was told by staff that I was not fit enough to be there and should be in the support group.

My appeal was not granted so I automatically was put forward for an independent tribunal.

Benefits were stopped during April 2012 because I had come to the 12 month limit for receiving benefits.

I heard nothing but in July 2012 to my surprise I received a letter from DWP stating I was in the support group and my benefits were back dated to when they were stopped.

I was under the impression from various media sources that people on existing benefits would not be initially involved with the change over to the new PIP scheme and only new claimants would be effectuated by the new system.

Yesterday I received a letter from ATOS with a Limited capability for work questionnaire.

I was a bit shocked when I received this as I thought I would not be reassessed until at least 2015.

This could possibly affect my mobility, DLA and ESA payments.

The strain and stress that going through all this again all this in not doing my health much good and I fear for my future.

Can you please tell me why I am being reassessed so soon when the government said claimants in my position would not initially be affected.

Sorry I have rambled on a bit.
WELFARE REFORM COMMITTEE

YOUR SAY – LONG-TERM CONDITIONS

WRITTEN SUBMISSION RECEIVED FROM MARIE CURIE

1. Marie Curie gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end. In Scotland we run hospices in Edinburgh and Glasgow, which provide free specialist medical care for those with serious illnesses, and emotional support for their families, giving them the best possible quality of life.

2. Marie Curie Cancer Care is pleased for the opportunity to provide feedback to the Welfare Reform Committee’s call for evidence on welfare reform. Our response is based on our experience as a charity which specialises in providing end of life care across Scotland.

3. Marie Curie hospices often reflect the wider community. As such, we routinely deal with patients and families who have worries regarding benefits, housing problems and those with health and social problems. The charity also acts as advocates for patients and families by liaising with local authorities, as well as advising them on benefit entitlement and patient rights.

4. We would echo the Health and Social Care Alliance (The Alliance) point that there is the real risk that reform of welfare plunges people further into debt and face even greater social exclusion and ill-health. The Coalition of Care Providers Scotland (CCPS) report that welfare reform and public spending cuts will see more disabled people on lower benefit incomes, including many diagnosed with sudden illnesses like strokes or cancer. It is of concern to Marie Curie that many people with a terminal illness will find themselves in a situation where they require increased care provision but with less financial support.

**Housing**

5. Many people with a terminal illness need to have adaptations made to their homes. Many also need to make use of a spare room for carers or themselves if their condition requires it. An appropriate home environment is crucial in order to support a person with a terminal illness to stay in their home for as long as possible, including at the end of life.

6. Marie Curie staff are seeing a clear rise in the demand for advice from people in dispute with local councils over housing decisions, such as those around spare rooms. Families coming to terms with dealing with a terminal illness can have these pressures exacerbated by financial concerns around housing. Social workers in our hospices have already seen anxiety and upset in patients and their families over housing issues following a change in their circumstances after a terminal illness diagnosis.
7. In addition, bereaved family members are often tasked with a quick turnaround when emptying the former home of a loved one in social housing in order to make it available as housing stock. This can be distressing to carers and families trying to come to terms with bereavement and loss.

**Pressure on General Practitioners and health services**

8. Austerity measures and welfare reform are impacting heavily on GP practices across the country and especially in the most deprived areas with some seeing practices become a ‘dumping ground’ as other services are affected by cutbacks. A recent report on GPs experiences of austerity and its effect on patients and practices in deprived areas raised a number of issues affecting GP services. These related to benefit cuts; service cutbacks; and an increasing number of patients being taken off Employment Support Allowance (ESA) or Disability Living Allowance (DLA).

9. Changes to the benefit system are impacting on practice workloads. Practices described an “endless cycle” of appeals, during which time the patients’ benefits are reduced. Patients also need to spend time asking GPs for letters appealing against Work Capability Assessment decisions, practice time that would otherwise have been spent on health concerns.

**Financial help and advice for those at the end of life**

10. Most people who need care towards the end of their lives qualify for either Attendance Allowance (AA), if over the age of 65 and not in a care home, or Disability Living Allowance (DLA), if under the age of 65. During 2013, DLA has been gradually superseded by Personal Independence Payments (PIP). Anyone who isn’t expected to live longer than six months because of an illness can apply for DLA/PIP or AA under special rules. Under these rules, the claim will be given priority and will be dealt with more quickly whilst the benefit will be paid at the highest rate. People who are claiming under this special rule need to ask their doctor to complete a form.

11. Macmillan Cancer Support recently highlighted the fact that hundreds of terminally ill cancer patients are facing delays for their income support, ‘payments that previously took eight to 10 days are now taking eight to 10 weeks’. Such delays simply cannot be allowed for those with a terminal illness and will have devastating effects on both patient and carer. The DWP have stated under the new PIPs, terminally ill cancer patients should be “fast-tracked” – we welcome this commitment but it should be rolled out to include all those with a terminal diagnosis.

12. Signposting to those services that are in place to provide advice and support on financial benefits such as preparing wills, pensions, power of attorney must also become routine wherever a person is diagnosed with a terminal illness. Advice can help to protect those at the end of life from potential pitfalls that many may not be aware of. For example people may be unaware that their bank accounts will be frozen at the time of death and as such it may be helpful to put the account in joint names whilst some private or occupational pension schemes
won’t pay out any benefits to partners if the owner of the pension scheme wasn’t married meaning that the pension fund is lost.

13. Timely and appropriate advice on benefits/wills/bereavement services is hugely beneficial to those at the end of life as it ensures all parties involved in providing care have a clear understanding of the options available, how to maximise their income and who is best placed to provide advice on the next steps. Marie Curie are currently seeing a rise in people asking for advice on how to appeal against decisions from their local councils regarding benefit support. This is likely to increase as patients and families face reductions in benefit or unavailability in other community services.

The effects of a drop in financial help for those requiring palliative care

14. A disproportionate amount of the cuts are falling on benefits such as Disability Living Allowance and Scotland will suffer more than its fair share due to more people with impairments and long term health conditions than other areas of the UK. This could impact on those that are terminally ill.

15. The benefits system needs to recognise both the emotional and financial impact of those requiring end of life care and their families, many of whom may have to reduce their working hours in order to provide care.

16. A drop in financial help for those in need of end of life care might mean that patients could be forced to stay in hospital beds and hospice care settings because families cannot afford to care for their loved ones at home where they would most like to be.

17. As people find it harder to pay for care it is possible that government agencies will be required to uptake more responsibilities. This may result in a sense of disempowerment for carers because of a perceived lack of ‘ownership’ on the type of care their loved-one receives, the place of where that care will be delivered and a lack of choice when it comes to funeral arrangements.

Self-Directed Support

18. Terminally ill patients in receipt of social care services may be required to undergo a reassessment of needs, as part of the movement towards self-directed support. These reassessments may lead to patients receiving less care or a budget that does not allow them to purchase the same level of care as they previously received. Reassessment can also lead to delays in care received. We have heard of examples of patients being delayed discharge from a hospice as local authorities undertake a social care reassessment. For those who are terminally ill any delay can seriously affect their long term care and can even result in them not being discharged to be cared for at home where they would most like to be. We would urge the Government to ensure that all terminally ill patients receive social care assessments and reassessments as a matter of priority and that the care packages that follow meet the needs of the patient and their families.
19. Research tells us that the majority of people would like to die at home, but the majority are dying in hospital. Research carried out by Marie Curie suggests that caring for a patient to die at home costs the NHS considerably less than to die in a hospital. The Benefits and social care system should be set up and flexible enough to support patients and families to achieve this.

Marie Curie Cancer Care would be happy to discuss our response further if necessary.
Survey results from 102 people with Multiple Sclerosis (MS) living in Scotland on the impact of welfare reform (2013) [Results analysed from Disability Benefits Consortium Big Benefits Survey (2013)]

Multiple Sclerosis (MS) is an incurable and complex long-term neurological condition that attacks at random. Symptoms of MS are often distressing and debilitating and can include intense pain, problems with mobility and co-ordination, depression, fatigue, incontinence, and loss of vision. Most people are diagnosed with MS between the ages of 20 and 40, during some of the most important, formative – and economically active - years of their lives.

Life for a person with MS is unpredictable. Some experience periods of relapse and remission, for others it follows a progressive pattern from onset. Even those with relapsing-remitting MS typically experience increasing disability and morbidity.

The figures and comments below are taken from a large-scale survey undertaken earlier this year by the MS Society in conjunction with other Disability Benefits Consortium members. There were over 100 responses from people with MS in Scotland. The data from these respondents are summarised below.

**Results from the survey**

**Impact of MS on employment**

80% of respondents were not in employment.

Those who were in employment tended to say that their condition limited the range of jobs they could do and the number of hours they could work. However, many of those who were in employment reported that they felt supported by their employer to remain in work.

A number of people who were not working at the time of completing the survey said that they wanted to be in employment but that employers’ attitudes made it hard to find a job.

A significant number of people who responded reported that their condition meant that they could not work and that working would have a detrimental impact on their health.

**Experiences of attending a Work Capability Assessment**

17 people had been through the WCA process, several of whom had been through it twice.
Only one individual had been made aware of the option to request a home visit as an alternative to travelling to the assessment centre. Sixteen people reported that they did not know this was an option.

**Half of those who attended an assessment centre said that the centre was not fully accessible.** Half of the respondents also reported that their assessment appointment was not on time.

“**I was left waiting for three hours and had to be woken up by my friend to complete the assessment**”.

“I had to get my husband to take a day off work to help me get there and move around in the building”.

“There was no information on my letter saying that I could have a home visit. My appointment was one hour late which led to even more stress”.

“The office I had to go to had no hand rails or ramps”.

“Where they hold the interview is not easily accessible. It is down a cobblestone street with no parking. The building is extremely tatty and run down with old furniture which caused me to be extremely sore for the rest of the week. My appointment was cancelled and re-scheduled causing stress and on the two occasions that I attended the doctors were running late up to 40 minutes.”

**Experiences of the WCA interview**

**All respondents unanimously declared that the interview was stressful. 80% felt that the stress caused by the interview made their health worse.**

“It took me over three weeks to get over the stress of the interview”.

Only a small minority said that the additional evidence they submitted in advance or on the day was taken into account, with the vast majority strongly disagreeing that this evidence was accounted for.

The length of the interview was also reported to be an issue with the majority of respondents feeling that there was not enough time for the assessor to learn about the symptoms of the condition that affected their ability to work.

Worrying, most people said that the assessment did not take account of how their symptoms are affected by repeat activity; and / or how they may fluctuate from day to day. These are critical aspects of MS symptoms and are pertinent to an individual’s ‘fitness to work’.

“I felt that words were being put into my mouth and the person did not take into account how tired/exhausted I was on the day. When I answered a question it was answered with a “but it could be worse”. I felt as if I was begging for something, and I was made to feel like a liar as if I was making excuses for not wanting to work.”
Less than half of those who had an assessment saw a copy of their assessment report. Of those who did, 70% did not feel it accurately reflected the answers they gave in the interview.

“There were quite a few things in the report that I didn't say or do”.

85% of those who appealed the decision to place them into the work-related activity group were successful in overturning the decision.

Experiences of those who were assessed as ‘fit to work’

59% of people assessed as ‘fit to work’ were not offered any subsequent support to help them get back to work.

The support offered to the remaining 41% mainly consisted of an interview at a Job Centre or Job Centre Plus, often with no follow-up after. No one reported being helped into employment as a consequence of their assessment. Several people explained that the employment advisor had suggested that they were clearly not fit for work and instead advised on how to appeal the WCA decision.

Impact of ‘bedroom tax’

Ten people reported that they had been directly affected by the ‘bedroom tax’. Six of these people who faced leaving their home or paying the tax had had their homes specially adapted for their disability, e.g. with a wet room or stair lift.

The reasons given for needing their ‘spare room’ included: using it to store equipment related to their condition or disability; not being able to share a room with their partner because of their condition or disability; and needing it for overnight carers who help with care needs related to their condition.

General comments on the impact of welfare changes

“I feel this has been rolled out far too quickly without much thought to the individual and the people who are assessing need better training!”

“I do not think the government takes MS as seriously as more visible disabilities or illnesses.”

“I worked for the DWP for 16 years before being accepted for medical retirement as I was no longer fit to work. How the DWP can 5 years later think I will be fit to work within a year I can’t work out!”

“The points system doesn’t work for illnesses which change day to day, it doesn’t take into account things like fatigue. Common sense needs to come into it not just rigid boxes and numbers. If you have a chronic, incurable and progressive condition and are not fit to work now then you are not going to be fit to work within a year.”
“Even though I have worked for the community all my life, the community now sees me as a scrounger. I have contemplated suicide because of the benefits cuts and the public’s attitude towards me.”

“I feel abandoned by society and vulnerable. There is most definitely a hardening of attitude towards the disabled and that means that many of us are withdrawing from society and becoming reclusive and invisible. I even feel unable to bother my doctor as I am being judged. I am no longer sure I have a secure future.”

“The small number of people who abuse the benefits system have left us all tarred with the same brush. The changes to the system hurt the most vulnerable in society.”
Annexe C

18 September 2012 – Your Say session

Evidence taken from:
Norman Gray
Janice Scott
Henry Sherlock

Official Report (Cols 238-271)
Papers
Minutes

5 February 2013 – Your Say session

Evidence taken from:
Marlene Hepburn
Lesley McMurchie
Ian Megahy

Official Report (Cols 514-544)
Papers
Minutes

10 September 2013 – Your Say session

Evidence taken from:
Anne Bradley
Lyndsay Ferry
Scott Wilson

Official Report (Cols 836-855)
Papers
Minutes

18 February 2014 – Your Say session

Evidence taken from:
Audrey Barnett
Donald McKenzie
Rosena McKeown
Fact-finding visit to DeafBlind Scotland – 25 February 2014