Written evidence from

Participation and Practice of Rights (PPR)

to the

Independent Review of the

Personal Independence Payment Assessment Process

Date: 15 March 2018

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SUMMARY AND RECOMMENDATIONS

- People with physical and mental health disabilities have a human right, codified in international human rights law, to be provided with the assistance and support they need to participate equally in all aspects of society. This includes a right to financial support, which, since June 2016 has taken the form of a Personal Independence Payment (PIP).
- There is incontrovertible evidence that the operation of PIP, in all of its aspects, is denying people their human rights, including but not limited to their rights to dignity, non-discrimination, information, due process, respect, a decent standard of living, physical and mental health. From causing enormous anxiety and distress, at its worst it is exacerbating people's physical and mental health conditions to a point of despair which has driven people to take their own lives.
- Since the commencement of its roll out in 2012 there has been an avalanche of damning reports, ranging from individuals affected, the advice sector, parliamentary inquiries and United Nations bodies, all of which conclusively demonstrate this lack of human rights compliance. Most recently, the Westminster Work and Pensions Committee inquiry into PIP concluded that the process needs '*urgent change*'.
- There are a higher proportion of people with disabilities in the north of Ireland than in other jurisdictions across the UK, partly as a result of both direct and trans-generational impact of the conflict.
- The mitigations measures, introduced under the Welfare Reform Act 2015, are temporary only and do not address these underlying issues.
- All of this underscores the urgent need for this review not to simply '*tinker at the edges'* of PIP, but to seriously get to grips with the fundamental failures in how it is operating in our particular context and to put forward credible, human rights compliant proposals for how these can be addressed.

- **Central to these failures are the following issues:**
  - the lack of any *due process* in the assessment process. At present the process routinely excludes the medical evidence and/or expert testimony, personal testimony and essential criteria. These three components are essential to any decision to award PIP.
  - the lack of an *impact assessment* prior to a decision being made.
  - the outsourcing of the PIP assessment to a private, profit driven company
  - the lack of appropriate training, qualifications or compliance with professional standards by health care professionals undertaking the assessments.
  - the failure to give primacy to the evidence from the person's GP and/or other health expert.

  - the failure to give people the opportunity to 'tell their own story' in narrative form and, alongside evidence from the person's GP, to give primacy to this evidence.

- The Right 2 Work: Right 2 Welfare group (R2W), which has campaigned for decent jobs and social security protections, has developed a set of proposals, called the *People's Proposal*, which if implemented in checklist format, would address all of the above failures. The People's Proposal is supported by all the political parties bar one, and by a majority of the District Councils, as well as gaining broad support within civic society.
- **Based on all of the evidence documented in this submission, PPR does not believe that the current PIP assessment process is capable of being reformed. We are therefore calling for the scrapping of the current PIP assessment process , in favour of a genuine, person centred, human rights compliant process, one which places evidence from the person themselves and those medical professionals they are known to, at the centre of that process.**

Pending the scrapping of the current assessment process and its replacement by the type of process described above, we make the following interim recommendations which must be acted on without delay:

1. The People's Proposal for due process and impact assessments should be incorporated into PIP decision making as a checklist to be completed by Decision Makers.
2. End the outsourcing of social security to private companies, including the outsourcing of PIP assessments.
3. All health professionals involved in PIP assessments should be appropriately qualified and trained, including accredited training in mental health and suicide prevention. Furthermore, they should not engage in any actions which would result in a breach of their professional standards.
4. Medical evidence from a claimant's GP should be given primacy in the assessment/decision making process, in other words, it should be mandatory that assessors obtain the claimant's file and give it primacy in the assessment. The assessor should also be obliged to obtain other relevant expert reports, as identified by the claimant. The cost associated with obtaining these reports should be borne by the Department/contracted bodies.
5. The assessment should facilitate the claimant telling their 'own story' of their disability and how it affects them in narrative form, rather than forcing them to answer tick box type questions, many of which claimants find irrelevant, confusing and misleading, as well as being invasive and deeply distressing.
6. All face to face PIP assessments should be routinely recorded by Capita, with the option of opt-out being provided. The cost of such recordings must be borne by the contractor/Department for Communities and not by the claimant.

1. Participation and Practice of Rights and the Right 2 Work: Right 2 Welfare campaign

Participation and Practice of Rights (PPR) is a human rights organisation located in Belfast. Established in 2006 by the late Inez McCormack, trade union leader and human rights activist, PPR supports marginalised groups to use human rights tools to realise their social and economic rights. In 2012 PPR's unique human rights based approach was recognised by the United Nations Office of the High Commissioner for Human Rights as a good practice example of how communities can claim their rights.

The Right to Work: Right to Welfare Group (R2W) is a group of unemployed people who have been campaigning since 2012 against benefit sanctions and for human rights protections in the social security system, as well as for the creation of real jobs through the use of public procurement.

The R2W group has developed a model for decision making within the social security system that is based on international human rights principles and standards, called 'the People's Proposal'. Since 2016 the R2W campaign has been actively lobbying for the incorporation of this model by the Department for Communities.

The People's Proposal is supported by all except one political party, by the majority of District Councils, by major trade union bodies including NIC-ICTU and NIPSA which represents social security staff. It also has widespread support across civic society, including from the advice sector, the community and voluntary sector and from sick, unemployed and disabled people themselves.

In 2016 members of the R2W group briefed members of the UN Committee on Economic, Social and Cultural Rights in Geneva during the Committee's examination of the UK government under the UN Covenant on Economic, Social and Cultural Rights.

PPR supports R2W in their campaign – this submission is directly informed by the R2W campaign.

2. Context

This review of PIP, required by the welfare reform legislation introduced in 2015, follows on from two reviews of PIP which have been conducted by the DWP, also undertaken in line with legislative requirements. **The context in the North of Ireland is significantly different however and must fully inform this particular review.**

The North of Ireland has a significantly higher proportion of people living with physical and mental disabilities than in other jurisdictions in the UK.

The north of Ireland is a region coming out of conflict, with many legacy issues arising, including greater levels of poverty and unemployment[1], the result of decades of underinvestment. The Commissioner for Victims and Survivors has estimated that 213,000 people experience significant mental health problems as a result of the conflict. It is also estimated that at least 40,000 individuals were injured during the conflict, many of whom have acquired disabilities as a result of those injuries. A World Mental Health survey found that the North of Ireland has the highest levels of PTSD in the world[2].

There is evidence that the Tory narrative around welfare reform which frames the debate as being one of '*strivers versus shirkers'* has gained traction in public discourse in the North of Ireland as well.[3] One such explanation posited for the higher levels of people claiming disability benefit in the North of Ireland has been to characterise it as being caused by people simply '*wanting to lie in their beds all day*', thereby removing the real context which includes almost a quarter of a million people suffering from mental health problems as a result of the conflict.

This ideology has been combined with the outsourcing of the assessment process for PIP to private companies that are profit driven. The result has been the inexorable rise of a profit making, punitive, victim blaming and shaming culture within which PIP is administered. It was only as a result of combined pressure from campaigners and from the Westminster Work and Pensions Select Committee that DWP dropped its target of 80% for upholding original PIP (and ESA) decisions at the first stage of appeal.[4] This profit driven target was described by Mr. Henry Brooke, a former judge and member of the Access to Justice

[1] 370,000 people live in poverty, including 110,000, or 23% of children. The North of Ireland has higher levels of unemployment and lower employment rates than elsewhere in the UK. The proportion of people in poverty in unemployed households has increased slightly over time, in contrast to the UK. https://www.jrf.org.uk/report/poverty-northern-ireland-2018
[2] http://www.bbc.co.uk/news/uk-northern-ireland-16028713
[3] https://www.belfasttelegraph.co.uk/news/northern-ireland/number-of-people-claiming-disability-benefits-in-northern-ireland-climbs-to-a-record-high-new-figures-show-31481561.html
[4] http://www.politics.co.uk/news/2017/05/16/dwp-sets-80-benefit-appeal-rejection-target

Commission as an '*absolutely outrageous interference*' with the rule of law.[5] **The Department for Communities has not as yet clarified whether it has dropped its intention to introduce similar targets for Mandatory Reconsideration.** [6]

Despite denials by government both the DWP and the Department for Communities that the intention behind the replacement of DLA with PIP was solely to slash the social security budget for supporting people with disabilities and long term health conditions, when one examines the approach taken in the PIP assessment it is difficult to reach any other conclusion. The dragnet approach being adopted, rooted in a punitive ideology that sets out to 'catch people out' is both reprehensible and wholly unnecessary given the robust fraud prevention resources in place by both DWP and the Department for Communities.

These then represents some key contextual factors within which PIP operates in the north of Ireland. Added to all of this, the recent inquiry by the Westminster Work and Pensions Select Committee brought to light the scale and depth of abuses of disabled people across the UK through the PIP assessment process.

Rather than approaching the Review as if it were happening within a neutral context, full consideration must be given to how the above context impacts on the day to day operation of PIP. The Review report must provide clear evidence of how this particular context has been factored in to its work.

3. Due Process

Social security entitlement is a right which is protected under Article 9 of the UN Covenant for Economic, Social and Cultural Rights. This right has been described as being '*of central importance in guaranteeing human dignity for all persons when they are faced with circumstances that deprive them of their capacity to fully realise their Covenant rights*'.[7] General Comment No 19 provides a more detailed interpretation of the obligations placed on the government arising from Article 9. It makes clear that any interference with an individual's right to social security must be subject to due process.

The components of due process are set as follows

(a) An opportunity for genuine consultation with those affected
(b) Timely and full disclosure of information on the proposed measures

[5] https://www.google.ie/amp/s/sirhenrybrooke.me/2017/05/15/mandatory-reconsiderations-and-the-rule-of-law/amp/

[6] Freedom of Information response received by PPR from Department for Communities; reference number: DFC/2017-0184

[7] United Nations Economic and Social Council General Comment No 19 The Right to Social Security (article 9) E/C.12/GC/19

(c) Reasonable notice of proposed actions
(d) Legal recourse and remedies for those affected
(e) Legal assistance for obtaining legal remedies

4. An opportunity for genuine consultation with those affected

The 'tick box' nature of the PIP assessment as it operates is the very antithesis of the 'genuine consultation' which people are entitled to. Claimants report that they are forced to respond to a barrage of unseen, multiple choice questions, many of which are meaningless and irrelevant to their condition and situation, as well as being invasive and deeply distressing. When they attempt to explain how their disability affects them in various aspects of their lives, they are stopped and forced to return to answering tick box questions.

It has now been well documented that the reports compiled by assessors frequently do not represent an accurate or truthful representation of how the claimant's disability affects their ability to function on a daily basis. The Work and Pensions Select Committee inquiry received a record number of submissions, large numbers of which described the 'reality gap' between a person's story and the assessor's report, characterised by the Committee as a '*no dog, can't walk'* approach to assessments. According to the Committee, this high level of inaccurate assessments translates into '*human costs to claimants and financial cost to the public purse'*. [8]

The Work and Pensions Select Committee inquiry found that PIP assessments reports compiled by Capita were rated as '*unacceptable*' in as many as 56% of cases, a rate that was massively in breach of the 3% target for unacceptable reports set in the PIP contract by DWP.[9]

Right 2 Work has supported a number of claimants to challenge factually incorrect reports and has compiled evidence of assessors' reports which have borne little or no relationship to the reality of a person's disability and how it affects them. Please see **Appendix A** for case studies.

What happens in practice is that within 72 hours of meeting a claimant and asking 12 descriptor based questions, a Capita assessor sends a report and recommendation to the Department for Communities Decision Maker, who will in effect 'rubber stamp' the recommendation without ever engaging directly with the claimant.

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[8] Right 2 Work has supported a number of claimants to challenge factually incorrect reports and has compiled evidence of assessors' reports which bore little or no relationship to the reality of a person's disability and how it affected them. Please see Appendix A for case studies.

[9] https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/news-parliament-2017/pip-esa-full-report-17-19/

A central problem in all of this is the failure of the PIP decision making process to give primacy to evidence from a claimant's GP or other relevant health professional, a vital element of any meaningful consultation. Right 2 Work has supported people to access their medical file under the Data Protection Act, only for its contents to be ignored by the assessor. At present assessors may obtain, but are not obligated to do so, information on a claimant from their GP. Instead claimants are 'invited' to send further evidence as part of their claim. The cost of obtaining their GP file, which ranges from £10 to £50, is borne by the claimant.

The Royal College GPs has criticised this approach, stating that "*as a general principle, putting the onus on the claimant to gather medical evidence carries risk and would be contrary to other similar processes such as housing requests or bus passes on medical grounds*". [10]

The Royal College GPs also drew attention to the conflict that is created by the existence of a contractual obligation on them to provide information as requested by DWP (or in this case Department for Communities) "*in this context GPs act on behalf of the DWP and as a consequence tend to provide only the minimum necessary factual information".* The five working day turn around for completion of forms for the DWP was also identified as insufficient, especially in circumstances where the claimant's GP may be absent.

The Work and Pensions Select Committee inquiry report recommended that the Department introduce a checklist system, requiring health care professionals to confirm whether and how they have used each piece of supporting evidence in compiling their report. Decisions not to use particular pieces of evidence supplied should be noted and justified. **While this recommendation should be implemented without delay in the interests of introducing some transparency into an opaque process, the solution is to make it mandatory for PIP assessors to obtain a person's medical file from their GP as well as any other relevant health reports. Consideration of such evidence must then be prioritised within the assessment process. The administrative costs attached to this to be borne by the Department for Communities.**

[10] http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/work-and-pensions-committee/pip-and-esa-assessments/written/75621.html

5. Timely and full disclosure of information on the proposed measures

Evidence gathered by Right 2 Work demonstrates that PIP claimants are currently being denied their right to information at all stages of the assessment process. They do not have sight of the descriptors on which the assessment is based. Claimants have described the questions they are asked during assessment, based on the unseen descriptors as irrelevant, confusing and misleading, as well as being invasive and deeply distressing.

Claimants are denied information as to the relevant qualifications and expertise of assessors. When they have asked for this information they have been told by assessors that they don't have to provide that information, despite their professional code stating otherwise.[11] Despite this issue having been raised back in 2015 by the DWP with Capita, the practice continues to be the denial of this information to claimants.[12]

The Department for Communities to date has refused to introduce mandatory recording of all audio assessments, despite calls from claimants, politicians and others for this to happen in the interests of transparency. The second independent review of PIP undertaken by Mr. Paul Gray on behalf of DWP concluded that the current provisions regarding recording are "*cumbersome and bureaucratic with many restrictions in place*" and that they '*set unreasonable obstacles*' in the way of claimants.[13] Mr. Gray recommended that in the longer term there should be "*audio recording of the assessment as the default, with the option of the claimant opting out*".[14] He noted that making audio recording the norm for face to face assessments would increase both trust and transparency. In response the DWP indicated that it would look at the possibility of a feasibility study with the aim of better understanding the costs and benefits of audio recording.

More recently the Work and Pensions Select Committee inquiry into PIP and ESA assessments concluded that "*recording the face-to-face assessment would go so far toward increasing transparency and restoring trust it beggars belief that this is not already a routine element of the process"*[15]. The Inquiry Chairperson Mr. Frank Field pointed to the cost-benefit argument in favour of mandatory recording *"the cost of providing a record of the assessment is surely nothing compared to the benefits of restoring trust. Those benefits should include far fewer decisions going to appeal – and being overturned there - at considerable legal expense to taxpayers*" [16]

[11] https://www.pprproject.org/first-do-no-harm-health-regulatory-bodies-must-act-in-relation-to-pip-and-wca-assessors
[12] https://benefitsandwork.co.uk/news/3079-dwp-tells-capita-pip-assessors-must-reveal-qualifications
[13] www.gov.uk/government/publications/personalindependence-payment-pip-assessment-second-independent-review
[14] Ibid recommendation 4
[15] Op cited at note 10
[16] Ibid

In response to public criticisms about the lack of transparency engendered by its refusal to have assessments routinely recorded, the Department for Communities simply suggested that all claimants being assessed could purchase two cassette dictaphones.[17]

6. Legal recourse and remedies for those affected

One of the fundamental safeguards that must form part of any administrative decision making process is access to legal recourse and remedies.

The introduction by the Department for Communities in June 2016 of internal Mandatory Reconsideration (MR) is widely seen as deliberately designed to 'choke off' resource to appeals by claimants. The rate of success at the MR is extremely low. From 2016-2017, of the 11,070 MRs registered, only 18% of new claims and 23% of reassessed claims resulted in a change to the original decision.

It was only as a result of combined pressure from campaigners and from the Westminster Work and Pensions Select Committee that DWP dropped its target of 80% for upholding original PIP (and ESA) decisions at the first stage of appeal.[18] This profit driven target was described by Mr. Henry Brooke, a former judge and member of the Access to Justice Commission as an '*absolutely outrageous interference'* with the rule of law.[19] **The Department for Communities has not as yet clarified whether it has dropped its intention to introduce similar targets for Mandatory Reconsideration.** [20]

The high rates of success by PIP claimants who do appeal to a higher tribunal underline the blocking intent of the Mandatory Reconsideration process. Most recent figures from England indicate that 69% of PIP claimants have won on appeal in the past three months[21]; Department for Communities figures indicate that a smaller percentage, around one third, of appeals are successful.[22]

In addition, the impact of a claimant having proper representation in an appeals process can be very significant. Advice NI has published figures which indicate that claimants are twice as likely to have a successful outcomes at Oral Hearing (for all social security appeals) if they have a representative.[23]

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[17] www.irishnews.com/news/2018/01/06/news/stormont-tells-pip-claimants-buy-your-own-audio-equipment-for-assessments-1226159/

[18] http://www.politics.co.uk/news/2017/05/16/dwp-sets-80-benefit-appeal-rejection-target

[19] Op cited at note 5

[20] Op cited at note 6

[21] http://www.guardian-series.co.uk/news/national/16074617.Disability_benefit_claimants_now_winning_69__of_cases_at_appeal/

[22] Freedom of Information response from Department for Communities to BBCNI; Reference number: DFC/2017-0239

[23] https://www.adviceni.net/blog/social-security-claimants-urged-seek-independent-advice

As highlighted by the Work and Pensions Committee, there is a huge human and financial cost attached to a flawed system, one which sees a significant proportion of original, incorrect decisions overturned on appeal. The fact that Capita has only issued one verbal or written warning over the quality of a Disability Assessor's assessment report[24] is a real indictment of the Department of Communities' failure to ensure that sanctions apply, including to their own Departmental Decision Makers, for failure to carry out their duties with due diligence.

7. Lack of impact assessment

General Comment 19 stipulates that '*under no circumstances should an individual be deprived of a benefit on discriminatory grounds or the minimum essential level of benefits as defined in paragraph 59(a)*[25]

Disabled people experience additional costs in most areas of everyday life, from major expenditure on equipment essential for independence, to ongoing higher expenses for, for example, food, clothing, utilities and recreation. The provision of PIP is intended to help claimants with the additional cost of a disability. These costs differ depending on the nature of a person's disability but have been calculated as ranging from £1,513 weekly for a person with high-medium mobility and person support needs to £448 for a person with intermittent or fluctuating needs.[26]

Yet the Department for Communities is failing to conduct any impact assessment before making a decision to deny disabled people additional financial support. The Department confirmed in a Freedom of Information response to PPR that it does not carry out any specific impact assessment on the impact on PIP claimants with a mental health condition, despite almost four in every ten PIP claimants falling into this category.[27] The impact of failure to award/removal of PIP from claimants on any dependent children is also not assessed, despite clear obligations on government to do so under the UN Convention on the Rights of Child.[28] **These failures leave the Department for Communities in breach of its obligations under a number of UN human rights treaties and leave disabled people at real risk of poverty and further exclusion from society.**

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[24] Freedom of Information response provided by the Department for Communities to BBCNI 24 October 2017; Reference number: DFC/2017-0253

[25] Op cited at note 7, paragraph 78

[26] https://www.jrf.org.uk/report/disabled-peoples-costs-living

[27] Response from the Department for Communities to a PPR Freedom of Information request Reference No: DfC/2017-0239.

[28] https://www.pprproject.org/throwing-shapes-benefit-sanctions-and-the-new-programme-for-government

8. **PIP assessments driven by profit motive**

The PIP contract was awarded to Capita in November 2012 for a 5 year period. Capita is the largest outsourcing company in the UK, with almost a third of the market share of business, and revenue of £4,897.9 m in 2016.[29] Capita has been awarded a dizzying number of public sector contracts across the UK, ranging from schools, prisons, health sector and the social security sector, everything and anything from managing patient records to collecting TV licence fees, 999 calls, and most recently, a 7 year PSNI contract to provide command and control systems.

The estimated value of its PIP contract in the North of Ireland is £59,253,626. The Department of Communities refused to provide an MLA with information on payments to Capita, on the grounds of commercial sensitivity, despite this information being available in relation to the Capita contract with DWP.[30] **Despite Capita's contract due to end in November 2017 the Department for Communities has not made public any information as to the future of this contract, or indeed why Capita is still delivering it.**

The delivery of public sector contracts by large private outsourcing companies such as Capita, driven by the profit motive, are inherently associated with lower quality and higher cost. The initial estimate for the PIP contract for DWP was £512million but has risen to £700million over the 5 year contract. It is likely that a similar pattern will be repeated with the Department for Communities contract.

The personal testimonies gathered by the Right 2 Work group, included in **Appendix A** speak to why profit should never be allowed to become a motive in what should be highly skilful, sensitive and empathetic assessments of the needs of vulnerable people for additional support. It is clear that the decision making process, where Capita assessors act as 'messenger' between the claimant and the Department for Communities is fundamentally flawed and wide open for corruption by profit driven companies seeking to meet targets.

The avalanche of personal testimonies from PIP claimants, published by the Work and Pensions Select Committee but also in the media, underscore this message.

In response to the evidence presented to it, the Work and Pensions Select Committee inquiry dubbed the PIP assessments conducted by private companies as '*opaque and unfriendly*' and concluded that "*the current contracts have not made the system fairer, have not made it more transparent and have not made it more efficient*".[31]

The Work and Pensions Select Committee recommended that government should be prepared to take assessments 'in house'. The Scottish Executive has done so already, with

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[29] https://corporatewatch.org/capita-company-profile/

[30] Written response to an Assembly Question by Minister for Communities Mr. Paul Givan to Mr. Gerry Carroll MLA ; reference number AQW 8285/16-21

[31] Op cited at note 9

its decision in 2017 to ban all private companies for carrying out benefit assessments and work is ongoing to establish a new Social Security Agency based on principles of dignity and respect. [32]

Bringing the delivery of PIP assessments back within the public sector will not in and of itself ensure that claimants' human rights to due process and impact assessment are respected, protected and fulfilled. However, it would remove the profit motive from these assessments, which would certainly be a step in the right direction.

9. Lack of relevant training, qualifications and compliance by PIP assessors

Criticisms have repeatedly been made of the lack of relevant qualifications and expertise of health assessors required to properly assess the full range of complex physical and mental health conditions claimants present with. Capita uses a generalist assessor model with assessors drawn from a range of professions including nursing, physiotherapy, occupational therapy and paramedics. Media articles have regularly highlighted the shocking lack of knowledge and expertise displayed by health assessors.

There is a mounting body of evidence linking increased mental ill health and rates of suicide to experiences of the PIP assessment. Department for Communities data indicates that 39% of all PIP claimants have a mental health condition. Despite this context, health assessors employed by Capita to conduct PIP assessments are not required to undertake any recognised, accredited suicide prevention training. Claimants with mental health conditions report being asked during their PIP assessment why they had not taken their own lives. Disability rights campaigners confirm that this is a standard question asked by assessors.[33]

PPR has cross-referenced the professional codes/standards which all health care professionals registered with the Nursing and Midwifery Council (NMC) or the Health Care Professions Council (HCPC) must abide by, with the PIP assessment process[34]. It has concluded that it would be impossible for those professionals to adhere to their professional codes/standards as the PIP assessment by its very nature involves breaches of a wide range of these standards, including the obligation to respect and protect human rights, to work within the limits of one's competence, to respect dignity, privacy and to be honest and trustworthy.

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[32] www.independent.co.uk/news/uk/politics/scotland-benefit-assessment-ban-private-companies-social-security-agency-department-work-pensions-a7706896.html

[33] http://www.disabilitynewsservice.com/pip-investigation-horrific-suicide-question-sparks-fresh-assessment-inquiry-calls/

[34] https://www.pprproject.org/first-do-no-harm-health-regulatory-bodies-must-act-in-relation-to-pip-and-wca-assessors

Right 2 Work has made written complaints to both regulatory bodies, as well as to the Professional Standards Authority (PSA) which oversees both the NMC and the HCPC. The PSA is currently undertaking a review of the workings of PIP and the role and responsibilities of statutory regulated healthcare professions in relation to the processes. The HCPC's response has simply been to reference the PSA review and indicate that it will await the outcome of this review and any recommendations that arise.

The issues raised above have direct relevance to this review of PIP. It presents a good opportunity to examine these issues and make recommendations as to the necessity for all health professionals to have the relevant training and qualifications.

10. Conclusion

The current PIP assessment process is fundamentally flawed and is causing great harm and distress to people with disabilities and long term health conditions. Based on all of the evidence documented in this submission, PPR does not believe that it is capable of being reformed. **We are therefore calling for the scrapping of the current PIP assessment process, in favour of a genuine, person centred, human rights compliant process, one which places evidence from the person themselves and those medical professionals they are known to, at the centre of that process.**

Pending the scrapping of the current assessment process and its replacement by the type of process described above, we make the following interim recommendations which must be acted on without delay:

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3. All health professionals involved in PIP assessments should be appropriately qualified and trained, including undertaking accredited training in mental health and suicide prevention. Furthermore, they should not engage in any actions which would result in a breach of their professionals standards.
4. Medical evidence from a claimant's GP should be given primacy in the assessment/decision making process, in other words, it should be mandatory that assessors obtain the claimant's file and give it due weight in the assessment. The assessor should also be obliged to obtain other relevant expert reports, as identified by the claimant. The cost associated with obtaining these reports should be borne by the Department/contracted bodies.

5. The assessment should facilitate the claimant telling their ‘own story’ of their disability and how it affects them in narrative form, rather than forcing them to answer tick box type questions, many of which claimants find irrelevant, confusing and misleading.
6. All face to face PIP assessments should be routinely recorded by Capita, with the option of opt-out being provided. The cost of such recordings must be borne by the contractor/Department for Communities and not the claimant.

Appendix A – Right 2 Work Case studies

Please note that Case Studies for persons C, D and E are being submitted separate to this document. Each of these individuals has given their permission for their documentation to be submitted to the Department for Communities.

However, they have stipulated that any personal details contained in these documents must be kept confidential and must not be made public.

Please confirm in writing that the Department for Communities will comply with this requirement.

Person A **'*The report said* versus *my reality'***

Previously I received low rate care and low rate mobility under DLA but my health had significantly deteriorated since that award, with additional physical and mental health illnesses.

On applying for PIP I requested a home visit for assessment due to mobility issues and limited assistance to get to the assessment. The assessor arrived with a trainee that I wasn't notified of. They sat in their car on the driveway for ages while I was stood at my door waiting to open it so I had to go back and sit down as I can't stand for long. This was written up as though I'd exaggerated it.

The assessor tried to get me to reach my toes. I went down about an inch but had to hold onto the table to get back up and steady myself. I said I couldn't go any further as it hurt and I was told to try more and I refused. The report said I did this freely and unaided. I have multiple illnesses and medication, side effects and see a number of different specialists. I am well versed in these but the report said I was well able to articulate my illnesses as if this was a negative.

I lie on my sofa with a table in front of it with things I might need on it or leaning between it and the sofa, like my easy grip or my walking stick. The report said my stick was over a metre away and I easily reached it, when in fact it's within an inch or two of reach. The report said I was dressed appropriately and fairly well kept. I was in my pyjamas and dressing gown without my hair brushed or washed.

The report stated there were no signs of breathlessness on speaking, yet I was breathless and having to sip water throughout and my voice became huskier and raspy as the interview progressed.

The report stated I showed no delusional thought yet I talked about an ornament talking to me.

The report said I could bring my chin to my chest, I can’t but I have excess weight around my neck that gets in the way.

The report said I showed no signs of pain, yet I constantly moaned when any effort was made to move, which is due to pain. The report said I could put both hands behind my head, yet I wasn’t asked to do this.

The report said I remained alert and orientated throughout, yet I was visibly tiring as the interview went on, becoming very forgetful with the assistant and the interviewer both having to prompt words for me.

The report also said I go out with friends and attended a party recently with her husband. I had said I’d been out once in 6 months and went to the party but took a panic attack and had to be brought home within a half hour of arriving.

The report said I could walk more than 50 metres, yet I only walked about 5 metres with the aid of my stick to my front door and back. The report stated I suffered from both diarrhoea and constipation but I only have diarrhoea. I wasn’t awarded anything in either care or mobility.

At the PIP tribunal I was extremely anxious (because at a previous DLA tribunal I had an awful experience of being bullied and abused by the panel) and had my husband and friend with me. Everyone from the security guard, receptionist and panel members treated me with respect. It was a much more positive experience, although exhausting, embarrassing and in depth. I was awarded high rate care and mobility.

Unfortunately afterwards I was contacted and told that a set of my papers for tribunal had got lost in the post. These included copies of GP and psychiatry reports detailing very sensitive information. They had been sent by 2nd class post instead of registered post, which the Information Commissioners Office said they should have been sent by.

Person B ‘Entitled – the Assessment’

This is the transcript of ‘*Entitled – the Assessment*’, a live reading of a PIP assessment based on real life experiences, performed by Macha theatre company.

CLAIRE: Neil, have you got your ID on you?

CAROLINE: Is it ok if I record this?

CLAIRE: Writing it down?

CAROLINE: Writing it down yes, but can I record it as well?

CLAIRE: No, no. You can do, but you have to plan it in advance, you have to get written consent forms from different people, and it has to be recorded on a device which I can only explain, it records two copies, and you take one and we get left with one.

CAROLINE: Ok, I’ll just make notes.

CLAIRE: Yeah, you’re welcome to make notes. (TO *NEIL*) Do you know what to expect today? Do you know what’s going to happen?

NEIL: sorry?

CLAIRE: Do you know what to expect today, do you know what’s going to happen?

NEIL: Not really, I’ve been panicking about it all day.

CLAIRE: Ah that’s fine, don’t get yourself worried. We keep it as relaxed as possible, ok? We’re just gonna have a chat about your conditions. Have a chat about the history of them. How they were diagnosed. Then it just goes on to how they affect you on a day to day basis, ok. At the very end there’s a little physical assessment. But we’ll cover that in more detail.

NEIL: (to Caroline) Did you lift that form? Did we forget it?

CAROLINE: No I didn’t bring it.

NEIL: ah no.

CLAIRE: What form?

NEIL: The form, the original form that was sent out to be filled in. We’ve left it in your house.

CLAIRE: That’s ok.

NEIL: It’s just, it was filled in by somebody else. It basically gave all the details of my condition.

CLAIRE: That’s ok because it’s all on the system.

NEIL: Oh, ok.

CAROLINE: Can we send that in?

CLAIRE: It's been sent in.

CAROLINE: Oh it has been sent in.

NEIL: Oh it has?

CLAIRE: Yeah.

NEIL: Oh ok, that was just my copy of it.

(NEIL hands a list of his medication)

I got that yesterday. I've been recently diagnosed with gout, I was at the doctors yesterday, so that's just a summary…

CLAIRE: That's ok, your gout's in the system as well. Caroline who are you to Neil?

CAROLINE: I'm the mother of his daughter.

NEIL: And my next of kin.

CAROLINE: Sorry, is it Claire?

CLAIRE: Claire, yes.

CAROLINE: Thank you.

CLAIRE: Did you want to send this in Neil? (list of meds)

NEIL: Well I just thought it might help if you wanted to have a look at it.

CLAIRE: That is fine. I mean, I can look at it, but I'm not the one who makes the decision, so what we do is just take a photocopy of this on the way out at reception.

NEIL: Yeah I just thought it might help, to get something from the doctor.

CLAIRE: No yeah that's fine. We can't post it though, so we'll give you a freepost envelope and you just have to post it. It's bizarre but they don't like to take charge of those things. But I just need to know that you brought it in today so they know to expect it.

NEIL: all it is, is a summary with my medication/

CLAIRE: No, yeah that's fine/

NEIL: Something from the doctors surgery as opposed to just written on a form/

CLAIRE: Yeah that's fine, plenty of people send in their patient summaries.

CAROLINE: Do you need a copy of Neil's medical file, or is his medication enough?

CLAIRE: Medication should be enough, I mean I'm sure your medical file is probably *substantial*. Most peoples are. So it would be an awful lot to send in, I don't even know if your doctor would do that. It would probably cost you a small fortune to copy all the notes to send them in.

CAROLINE: But it's just if you're making a medical assessment, how would you make that without the medical file?

CLAIRE: Just on what we chat about. Your history of conditions. You'll see as we go along, don't you worry. We go into your history of conditions, we go into how they were diagnosed, how you're treated, who reviews you now, how it's managed now, anything in the future that's planned, so basically, you regurgitate your medical notes. Is all it is really.

CAROLINE: Ah I think my worry is because I know obviously Capita is set up to take people off the system who aren't eligible, and obviously Neil is, and it's just to make sure that we can send in all the information that's necessary.

CLAIRE: I mean by all means, if you want to, you're more than welcome to, you'd have to get that through…

CAROLINE: so we can send that in then, if we get a copy of that?

CLAIRE: Yeah.

CAROLINE: Ok. How long…when do we need to send that in before it goes to the decision maker?

CLAIRE: Will this will go off today, that's just my part of it. The decision maker will take however long they take to make the decision.

CAROLINE: Ok, so would we have to send it directly to him?

CLAIRE: Yeah probably, or you can send it in – I can check on the way down but I'm sure…I think it'll probably just go off to Limavady as well because it all gets scanned into the

system. So…when it gets scanned into the system, anyone can access it. Anyone that's looking into Neil's claim, can access the system, type in his reference number and bring it up, it goes into our system, the DFC use the same system – the decision makers, they work for the DFC and they're all linked into the same system so they can look at it still so..

CAROLINE: So, sorry, who would we send that off to then?

CLAIRE: Probably to this address still.

CAROLINE: Yeah?

CLAIRE: Yeah.

CAROLINE: That's great.

CLAIRE: I'll give you that envelope now.

CAROLINE: Thank you very much.

NEIL: That's the only bit I understand, youse are all talking about stuff (laughs)

CAROLINE: Sorry, I'll shut up (all laugh)

NEIL: It's really warm in here.

CLAIRE: That's me, I whacked the radiator right up because it was too chilly…

CAROLINE: It's really cold outside..

CLAIRE: It's the heat rising as well…

NEIL: I'm like that anyway, I overheat. I like the cold weather.

CLAIRE: So, in terms of your conditions, I've got that you were diagnosed with depression and anxiety.

NEIL: Schizo-effective disorder.

CLAIRE: But they're separate things?

NEIL: Sorry?

CLAIRE: They're put down as separate conditions? The depression and anxiety/

NEIL: The depression and anxiety, I'm on medication for both.

CLAIRE: Yeah but are they treated separately?

NEIL: No it's all the one condition/

CLAIRE: Ok that's fine, it's just on the form it was put down differently.

NEIL: The whole lot's tied together through my mental illness. As far as I'm aware.

CLAIRE: That's ok! If that's what you're under the impression of. That can sometimes happen sometimes, if you get someone else to fill in the form, they can misinterpret it, they can write it down differently, they can misinterpret it, but that's fine, we just change it now.

Neil do you remember roughly when that was diagnosed?

NEIL: Jesus…

CLAIRE: Just roughly…

NEIL: It would be roughly, 7 years ago.

CLAIRE: Ok. And do you remember who diagnosed it for you, now remember don't worry about names because we can't put names in.

NEIL: I don't know, I couldn't tell you names because I couldn't remember. I was diagnosed in hospital, I was hospitalised for a month.

CLAIRE: That is fine. Was it a psychiatrist would it have been?

NEIL: A psychiatrist, yeah.

CLAIRE: That's fine.

NEIL: It was the mental – the Mater mental, I don't even know what you call it.

CLAIRE: Ok so a mental health unit/

NEIL: The Mater psychiatric ward basically.

CLAIRE: Fine. And why were you admitted there for a month?

NEIL: Well I took what's called a psychotic break.

CLAIRE: Ok, were you there voluntarily or were you sectioned?

NEIL: Em… well what happened was I was sent first to – I don't know if you've ever heard of the Bell Doc –

CLAIRE: No…

NEIL: It's like an emergency doctors that like opens late for people/

CLAIRE: Oh yeah/

NEIL: And em, cos of the psychotic break I didn't know what was going on and they sent for people to take me to stay somewhere else, I think it was in the Holylands some place, some house – it's only patchy memories I have of it. And then they seen – they checked it, because they thought it was drugs first – they thought I was taking drugs and they checked me over and looked at my eyes and stuff and realised that it wasn't, it was an actual psychotic break, and the next morning they booked me into the Mater, and they drove me to the Mater. So it was the day after, the second day of the break. The psychotic break lasted for, I think it was about 4 days, wasn't it?

CAROLINE: Yeah.

NEIL: …as far as I can remember. And I was in hospital for a month and basically they tried different medications, it was sort of trial and error, and by the end of the month they reached a conclusion, my diagnosis, and the right medication, cos when they got the medication right it showed its effects and from that they were able to deduce my, my condition, and then I was diagnosed.

CLAIRE: Yeah. Yeah. And – when you were discharged and you were sent home, did then send you home with any sort of care package – did you have regular reviews, did you have a CPN/

NEIL: A CPN. I don’t see him anymore but it was 7 years of..CPN, I had about 5 different ones.

CLAIRE: Ok. How often did the CPN come see you?

NEIL: Em once a week.

CLAIRE: And when did that stop Neil, can you remember.

NEIL: It only stopped a few months ago, I had my last interview. My last CPN, I didn’t trust her/

CLAIRE: Oh ok/

NEIL: I couldn’t bring myself to talk to her so I *omitted* an awful lot of things/

CLAIRE: Right/

NEIL: /because basically, in my head, I just wanted out. See I used to get home visits/

CLAIRE: Yeah/

NEIL: /and then they changed it to this place a way up the Antrim Road and the woman that was doing it, I'll not mention her name but I just, I didn't trust her.

CLAIRE: Ok.

NEIL: It was actually my last, my last interview with her, or not interview, my last discussion with her/

CLAIRE: /yeah.

NEIL: /em, the last question she turned round and asked me was 'what was your diagnosis again', this is after seeing her for a year and a half, so she didn't even know what I was diagnosed with/

CLAIRE: /Yeah.

NEIL: /and she was treating me, I don't know what the story was. I got discharged anyway. I'd be happy to go back to any other CPN that I used to have but I wouldn't go back to her because I just didn't trust her and she made me – my paranoia spiked when I was with her.

CLAIRE: Right, ok. Apart from your paranoia Neil, what other symptons would you get? How else does it affect you?

NEIL: Well paranoia and then my anxiety, my panic attacks – I take medication for them but still, Caroline can tell ya, I'd take panic attacks, especially in crowded places, with a lot of people, meeting new people, it's hard for me. Socialising is out of the question. I can't even get a bus. I don't feel safe on a bus. That's basically what it boils down to if you know feelings of unsafety. Em..what else..? Well, the depression, yeah, cos it's moodswings. Schizo Effective disorder is between Bipolar Disorder and Schizophrenia –

CLAIRE: mmm-hmmm.

NEIL: So my moods are up and down – I'm on mood stabilisers for them but again still, it's not like take the tablets and it's gone.

CLAIRE: No. It helps to manage… mmm-hmmm.

NEIL: The medication I'm on I think works. It's just some days… are an awful lot worse than others /

CLAIRE: ok..

NEIL: /and the medication can't hold it at bay.

CLAIRE: Ok yeah. How many days would you get like that, on the medication?

NEIL: Could be at least two days a week.

CLAIRE: Yeah? And are they days – how would it be worse? Are they days when you feel like you struggle to get out/

NEIL: Can't get out of bed.

CLAIRE: /of bed.

NEIL: I'm scared to get out of bed. I start to hear voices in the corridors outside me flat -

CLAIRE: Are they only on your *really* bad days you get your hallucinations…

NEIL: - yeah it's always, it's not even that I make out full sentences, it's I just get the feeling that they're targeting me. And the only way to deal with it is to lie in bed. To stay in bed. Caroline can tell you it'll be a whole day lying in bed. Yeah.

Caroline: That's what happened in the first breakdown you had. Neil went missing and we didn't know where he was. We phoned the place he was staying and they told me they put him in a taxi to the hospital. Because he thought people were outside to attack him. And when I finally tracked him down, I phoned different hospitals, I finally got through to the Bel Doc at the Matter and they said he's here, and the phone went dead. After hours of chasing him.

NEIL: I jumped up and hung up.

Caroline: Neil thought people had tapped into our phone and were trying to kill me and my daughter as well, so we had to manage that over that week as well.

CLAIRE: Have you ever had any previous thoughts of suicide or self-harm?

NEIL: I've attempted once. Threw myself into the Lagan.

CLAIRE: Ok, when was that?

NEIL: Oh that was a long time ago. That was before my diagnosis.

CLAIRE: That's ok, roughly how many years would you say?

NEIL: Maybe 13 years ago. I'm not even sure why I did it. It's not like I had a plan or anything like that. It just happened. Lucky enough some people stopped and saved me. I came round to myself while I was in the water and I actually swam to the edge. It was – do you know the Ormeau embankment –

CLAIRE: Yeah.

NEIL: Where the Lagan's really fast-flowing –

CLAIRE: Yeah.

NEIL: And I actually made it. It took me about half an hour to swim to the side and the people that stopped, they'd seen me – I think it was 8 o'clock in the morning or something like that, people were on their way to work and they helped me, and helped me home and things.

CLAIRE: That's good.

NEIL: There hasn't been any more attempts but the thoughts are always there. The thoughts come in –

CLAIRE: Yeah, do you make plans or is it just thoughts?

NEIL: No it's just thoughts. Like I could be sitting somewhere on a bit of a height and I can imagine myself –

CLAIRE: Ok.

NEIL: You know…I have a major fear of heights now because I just picture myself walking off a height or jumping off a height. And then I have, I get, continued intrusive voices anyway, that tell me – it's not even like it's a voice that I can hear like I'm not saying the devil's talking to me or anything, it's – I describe them as voices but I know they're my own thoughts afterwards, but it's like trying to get me to do something. It's like – nearly like having a panic attack. Em, I just envisage the worst scenario of what I'm about to do or what I need to do.

CLAIRE: Right, ok.

NEIL: Which is why when I do feel bad, I try to stay in bed. And Caroline would help there. She would phone me and make sure I'm ok, and try and get me out. She'd call over in her car and take me over, her and the child and sit with me and it just sort of calms me down and I come out of that, settled a bit.

CLAIRE: Ok. And then in terms of your ankle, I have you have a plate in your left ankle? When was that?

NEIL: That was – how many years ago was that? It would be the same. It would be about a year before I was diagnosed with my illness. Because I was living in a hostel when I was diagnosed.

CLAIRE: OK.

NEIL: It was maybe 6 months before that? I don't even think it was a full year. I'm not sure I'm not even great with dates and memory and stuff like that.

CLAIRE: Do you know what, it could even be on here. No, he hasn't gone back past – oh there it is, 2009, a fractured ankle. They did get it right, there you go. Fractured ankle, had surgery -

NEIL: Had surgery, it's just never been the same since.

CLAIRE: How so? Tell me how it still bothers you?

NEIL: Well it's just constant pain – some days are a lot worse than others. I think it's probably just arthritis setting in with it. It's never really been the same since the surgery. It's daily pain. But there's some days where it's extremely painful.

CLAIRE: Did you have post-op physio?

NEIL: No. Well – what they did was, well, I asked them to take me off the morphine cos I said to them, I wanna get out of hospital, and I'm not gonna have morphine at home so I'd rather get used to the pain. And then they let me, it was not that day but the day after, they took me out, cos I was on two crutches cos I couldn't put my left foot down at all, so I was on two crutches, I was basically walking on one leg –

CLAIRE: Right –

NEIL And what they did was they took me out to the back steps and asked me to walk up the two steps and walk back down the two steps, and that was the post-op physio.

CLAIRE: And they were happy.

NEIL: That was it.

CLAIRE: So are you in pain with your ankle everyday?

NEIL: Everyday.

CLAIRE: But then some days you're saying it's a lot worse.

NEIL: Somedays it's extremely bad yeah.

CLAIRE: And how many days a week would it be much worse?

NEIL: I couldn't even pinpoint it, it would be extremely bad for a number of days in succession and then the pain would ease for whatever reason, I don't even know why, that's why I just assume it's maybe arthritis and maybe the weather changing. But they told me the surgery, it was a complete success and all. It's just the remnants of having the metal plating and the screws, they're holding my bones together because it was a clean break across my ankle.

CLAIRE: And you said you were diagnosed with your gout just recently?

NEIL: Just recently yeah, well it was a phone diagnosis at first and then, em I was at the doctor yesterday. I went for blood tests and then my doctor, yesterday, he confirmed it. It was high levels of something, I don't know what it was, and he said it was definitely gout.

CLAIRE: So why were they doing blood tests?

NEIL: Because I phoned up about my foot. I didn't know what was wrong with it.

CLAIRE: So they did blood tests off of your symptoms and they said Oh it's gout.

NEIL: Yeah.

CLAIRE: fine. So it was literally just –

NEIL: See when I described what was happening, see my big toe, was broke a lot of years ago. Em, it flares up and it goes red and it really swells up, and I can't put my foot, I literally can't put it down on the floor/

CLAIRE: Right?

NEIL: On the right yeah. So I had to phone up, my doctors if you phone up between half eight and ten o'clock in the morning, you get a call back from the doctor and when I described it to him he diagnosed me over the phone, he said it sounds like gout, I'm nearly sure but we'll run some blood tests, and done the blood tests in my appointment and he said yes, that's what it is.

CLAIRE: Did they start you on medication?

NEIL: No, what we're gonna do is – remember it was only yesterday that we spoke so, we're gonna monitor it over the next 6 months and see how often it's occurring and decide whether or not it's medication that I need. Because if it's only happening every couple of months, at the minute it's only happening it feels like once a month, it flares up and lasts for over a week if you understand. So at the moment it's only anti-inflammatory's, but I'll take them until I need them I don't even have to go through the whole course. So eh like from the last one was a load of weeks ago, I still have half the prescription so if it happened again I still have the tablets instead of me going and ordering excess tablets.

CLAIRE: Right, Ok.

NEIL: Yes so basically that's an ongoing thing it just has to be monitored and em-

CLAIRE: That's fine. And then you also put down you're an alcohol dependent.

NEIL: Yeah.

CLAIRE: How long has that been?

NEIL: Since the age of fourteen. 23 years.

CLAIRE: And is you GP aware?

NEIL: Yes.

CLAIRE: Have they ever referred you on to like Addictions NI or anything?

NEIL: I done that myself.

CLAIRE: Ok.

NEIL: Years ago. I got counselling for – it was about 6 months, or was it just under a year…6-8 months, something like that. Em…which was really helpful, it helped me understand a lot of things about my past which I'm not going to go into-

CLAIRE: No. You don't need to that's fine.

NEIL: Yeah it helped me deal with it so now I have – I don't like using the word control, but I'm – I'm not the same person as I was years ago, when it was drinking all day, every day basically.

CLAIRE: Ok.

NEIL: I was still coping with it, it was working. I think that's what helped me eh.. I think I was actually self-medicating myself, with alcohol.

CLAIRE: Right ok.

NEIL: When I was in hospital - I hadn't took a drink in 6 months, and that's when I had my psychotic breakdown, so…

CLAIRE: And are you still drinking now or are you sober now?

NEIL: I'm still – well, I would still have a drink the odd time, I wouldn't torture myself. I would have em…

CLAIRE: How often would you take a drink?

NEIL: Ach… you're talking once a month, twice a month maybe. And only a couple/

CLAIRE: And is it/

NEIL: /and all I drink, it's just beer. It's not spirits/

CLAIRE: and you just have a couple of beers, you're not/

NEIL: /That's it, no/

CLAIRE: You wouldn't drink/

NEIL: I set myself a limit. And when I get it into my, what I've told myself is/If I call in, maybe there's a football match on or something I might have two pints, but I tell myself going in that that's my limit/

CLAIRE: That's your limit, fine/

NEIL: /and because I know in my head I've told myself that's what I need, once I have them, there's no cravings, I'm satisfied, if you know what I mean, because that's what I set myself out to do.

CLAIRE: No, that's fine. That's good!

NEIL: and I feel it works in a strange way/

CLAIRE: No, good!

NEIL: /not sure if it would work for everyone, but it works for me.

CLAIRE: That's all that matters. What works for you. Going on to your medication then/

NEIL: Mmm-hmm/

CLAIRE: I've got you're on Zop-i-clone 3.75 once a month.

NEIL: Yes, it's a sleeping tablet.

CLAIRE: Do you find it helps?

NEIL: Em..well it does but, I still find it hard to sleep. I don't take it and all of a sudden bang, I'm asleep. It's..I take it maybe two hours before I go to bed, or when I'm intending on going to bed, it/

CLAIRE: It helps wind you down a bit/

NEIL: Yeah. You'll also see on there **co-tie-a-feen**, which is my anti-psychotic. That aids sleep as well, that's, so I'd be basically heavily sedated every night/

CLAIRE: That's fine/

NEIL: And in the mornings –

CLAIRE: Do you take you co-tie-a-feen just a night?

NEIL: Just twice at night, it works out 600 mg's a night. Two by 300 mg tablet.

CLAIRE: And then your Diazepalm 5 mgs? /

NEIL: Yes/

CLAIRE: Once a day/

NEIL: That's during the day, I take that in the morning.

CLAIRE: Do you find that helps your anxiety?

NEIL: Em..I think so, yeah. I think they give me that just to sort of try and keep me on an even keel because of the bipolar/

CLAIRE: Fine/

NEIL: I think so anyway/

CLAIRE: That's ok. And your Omeprazole, were you put on that because you were having reflux or is it just to help protect your stomach/

NEIL: I've a hernia.

CLAIRE: Oh ok.

NEIL: It's a hole in my diaphragm. So ah, yeah I take two of them tablets each day.

CLAIRE: And then your Fire-een? Do you still take that everyday? /

Neil: Every morning/

CLAIRE: 100mgs?/

NEIL: Even when I'm not drinking which is basically what it's for/

CLAIRE: Yeah/

NEIL: /but I take it every day anyway.

CLAIRE: /No, that's fine. And then your Def-a-cot? 250mgs?

NEIL: Twice a day/

CLAIRE: Twice a day. Do you find that's helping?

NEIL: Em..yeah that's the mood stabiliser so again that's to sort of keep my, equilibrium basically, instead of going into the depths of depression, or going too high, just to…that's what that's for.

CLAIRE: And then your by-gab-a-lin? What are you on by-gab-a-lin for?

NEIL: That's for the anxiety and panic attacks.

CLAIRE: Do you find it's helping? 75mg twice a day.

NEIL: Yeah…not really. They don't help a massive lot. It could be helping me more than I actually realise, I'm not sure, but it definitely doesn't stop them. I still take panic attacks pretty regularly so…

CLAIRE: Ok. Em, side effects – I've got down that you put down sedation and confusion. Do you take anything else over the counter, anything you buy yourself in the chemist?

NEIL: No. I don't like – I wouldn't even take a painkiller if I'd a headache.

CLAIRE: Oh ok.

NEIL: I'm not a big fan of having to take tablets but the condition I have, I've no choice.

CLAIRE: Yeah, no, that's fine/

NEIL: It's either that or another psychotic break. That'll land me in hospital and the whole thing starts all over again.

CLAIRE: And, do you live alone?

NEIL: I do.

CLAIRE: And where do you live? A house, a flat or bungalow?

NEIL: It's a flat.

CLAIRE: What floor are you?

NEIL: It would be the second floor? But there's handrails the whole way up.

CLAIRE: No lift.

NEIL: No lift, but when I say the second floor, it's not a massive high building, it's only, I think it amounts to 20 steps all in one…that's it…

CLAIRE: Fine..In your bathroom, do you have just a bath, just a shower, or is it a shower over a bath?

NEIL: I have a shower head. But…I can't get into the shower, I'm too scared, I'd panic..I'd freak out –

CLAIRE: Is it just a shower unit?

NEIL: It's a bath.

CLAIRE: A bath? Like a hand –

NEIL: A bath…and then one of the…shower head type things that you attach to the tap.

CLAIRE: Fine.

NEIL: So it's just used for cleaning the bath.

CLAIRE: Right.

NEIL: Em..yeah..I'm too scared to take a shower because I'm standing in the bath and start to freak out about my ankle, and sort of envisage myself falling –

CLAIRE: Ok.

NEIL: It's just a bath that I'd take..

CLAIRE: Ok. Have you ever been assessed by an OT, an occupational therapist?

NEIL: No.

CLAIRE: Have you bought anything to help you around the flat?

NEIL: No…well nothing really, only really sort of domestic stuff.

CLAIRE: No that's fine. Are you working at the moment?

NEIL: No I, I don't work. I can't commit to a schedule you see because of the medication, I don't, I sleep til, sometimes, sometimes like I said I'm too scared to get out of bed. Even when I'm not having the worst of days, the medication would have me sleep until lunchtime anyway.

CLAIRE: Ok. When did you last work? Have you ever worked?

NEIL: Oh yes!/

CLAIRE: When did you last work?

NEIL: /I worked my whole life until I took my breakdown

CLAIRE: Ok/

NEIL: /and that's when I stopped.

CLAIRE: What were you doing at the time? What work was –

NEIL: I was in bar, bar management. And all the rest. I was a barman basically for/

CLAIRE: Oh ok.

NEIL: /nearly 15 years I think it was.

CLAIRE: Do you drive?

NEIL: No.

CLAIRE: Have you ever driven?

NEIL: No.

CLAIRE: And how do you pass your days, what do you like to do?

NEIL: Well if I'm having an ok day, Caroline would generally come over and pick me up, and she'd have the child with her and we'd go and spend some time in their house, and sit with the child. Caroline would make dinner for me. And then, that's basically it most of the time. Sometimes my uncle would call over and he'd sit with me. He lives in the town centre, pretty close.

CLAIRE: Ok.

NEIL: I don't really get up to much, I basically just try to keep myself as calm as possible and –

CLAIRE: That's fine.

NEIL: I'm too worried about triggers.

CLAIRE: What would you do when you go to Caroline's and you see the child? Do you, you know - how old is the child?

NEIL: How old is she? She's coming 13.

CLAIRE: Oh ok.

NEIL: It's not going over and taking care of her and all that, it's not –

CLAIRE: Ah right! I was going to be like, what do you do? I was gonna be like, do you read with her? But probably not, you've passed that stage!

NEIL: We just sit. She's at that age now that she watches shows that you can watch with her. It's not torture. It's not wee cartoons, em..and she, she's brilliant. She's so

attentive. Like she knows all about my illness, I described it to her and told her, she's old enough now to know about it, she understands it so all we do is just sit. She'd be looking after me, she'd be making cups of tea and she loves her baking and all.

CLAIRE: Very nice. Being a baker, perfect.

NEIL: She makes her wee buns and cakes and pancakes and all that.

CLAIRE: She sends you home with little packages, very nice.

NEIL: Yeah…

CLAIRE: So you said before that Caroline would make the meals?

NEIL: Yeah.

CLAIRE: Is that pretty much all the time?

NEIL: Yeah, unless…the only other times would be junk food.

CLAIRE: Yeah? What takeaways, or would Caroline ever make you up a plate and send you home and you'd microwave it the next day/

NEIL: Oh I'd do that the odd time, yeah. I've a problem eating. It's eh…I find it very hard to get motivated so things like eating and bathing can be a problem for me.

CLAIRE: That's fine, we'll go through those. Don't you worry, we'll go through each activity in painful detail! Em…so, is that why Caroline makes most of your meals? It's that you just don't have, don't have any need to just get up and make yourself –

NEIL: Well I wouldn't. I'd sit for days without eating.

CLAIRE: Fine. When the food is made – so if you're at Caroline's and she makes food and sits in in front of you, would you then eat it?

NEIL: Em, yeah, sometimes it'll take a little coaxing. But I'd, you know… end up eating it if it's made and it's put in front of me. I mightn't eat a whole lot, I don't have a massive appetite these days, I used to have a really big appetite but these days not really. So I might only eat half the meal, but I'd eat something. Yeah, my diet's pretty poor…

CLAIRE: Yeah, and what about managing your medications, do you take your own medications, do you -

NEIL: Yeah, Caroline would remind me once a week and my uncle does as well, he'd phone me up and get it set up through the pill box –

CLAIRE: Ok.

NEIL: So am, I've been on them that long now, that once the pill box is filled, it's not too hard to take them. But like I need reminding still for it like. There's days I'll completely forget, or there's days I just say, I'll take it into my head 'I'm not taking my tablets today' for some reason and… but, I'm in contact with someone every day and I get asked pretty much every day 'are you taking your tablets' so…

CLAIRE: And getting yourself washed? How many times a week would you get yourself washed?

NEIL: Sometimes none, in all honesty.

CLAIRE: Yeah, that’s ok. And is that because you don’t have the motivation to do it or you find it scary to do it?

NEIL: It’s a little of both if that makes sense.

CLAIRE: Yeah.

NEIL: It takes a major sort of push either from somebody else or myself just to do it. Sometimes I’ll just sit there and it’ll be in my head and I’ll have planned to do it and I’ll just sit and sit and sit and sit and won’t do it. It doesn’t happen. And eh, I can sort of let myself go. And then…see to be honest…I’d maybe have a bath every couple of weeks.

CLAIRE: Ok, is that the average for you?

NEIL: Roughly, yeah.

CLAIRE: Yeah. Em..Can you manage your own toilet needs? Can you get yourself on and off the toilet and clean yourself afterwards?

NEIL: Yeah.

CLAIRE: Getting yourself dressed – would you get yourself dressed everyday?

NEIL: Not really no.

CLAIRE: How many days a week roughly would you say you get yourself dressed?

NEIL: Maybe four out of seven.

CLAIRE: And is that again, it’s just lack of motivation –

NEIL: Yeah, it’s like I said in the beginning, sometimes I just don’t get out of bed. Sometimes I get out of bed and I sit. Again, I just can’t do anything, I’m sort of lost in my own world –

CLAIRE: Yeah.

NEIL: Again, intrusive thoughts can come in to it. I just don’t bother basically. It’s not laziness!

CLAIRE: No!

NEIL: I wouldn’t describe it as laziness. It’s just, it’s hard to describe actually but I’m finding it ok now, for some reason I’m able to communicate with you at the moment..

CLAIRE: Good! And can you read ok?

NEIL: Yeah I’m an avid reader. In saying that I started a book there a few months ago and I haven’t picked it up since. And then there’s days were I read the entire day. I prefer books to TV. I’d rather read a book. Because it takes me away from..it’s escapism for me, you know what I mean/

CLAIRE: Yeah, it takes you out of your head/

NEIL: I go in.. I read fantasy novels/

CLAIRE: Oh ok.

NEILL: /so it's different worlds and different types of people and all. You just get lost in them wee stories. Basically it..it just helps me get through the day sometimes.

CLAIRE: Yeah!

NEIL: Just being lost in a different, on a different planet. (About Caroline) She'll probably tell you I'm always on another planet.

CLAIRE: And then mixing with people outside of the family.

Neil: Terrible. Terrible/

CLAIRE: That would be the anxiety, the paranoid side of things coming in/

NEIL: I just – socialising is just a no-no.

CLAIRE: Yeah.

NEIL: Even my neighbours where I live. I know a couple of them. But it's hello/goodbye. That's it. There's no socialisation. Like I said, even sitting on a bus is too much for me.

CLAIRE: How do you get around?

NEIL: Either Caroline gets me or it’s a private taxi. It’s the only way I can do it. Even in a private taxi, I don’t even talk to the taxi driver, I just sit there.

CLAIRE: And…managing your finances…do you? Are you aware of sort of incoming/outgoings/budgeting for food and bills?

NEIL: Well sort of. Budgeting I’m not great at. And food and bills …because like I said I don’t really watch TV and stuff, my electricity would last for a long time. Em..so I would again, Caroline would help me or my uncle, make sure you had, you know the way you get your electric and your gas and all the rest. Like I said my gas is off a lot of the time because I don’t bathe as often as I should.

CLAIRE: And…why do you find they need to help you? Is it just to get out of struggling.. to sort of engage with the whole.. sorting finances?

NEIL: Sorry…could you repeat that?

CLAIRE: Just why do you find that your family need to help you? Why does Caroline or your uncle need to help you sort of manage it?

NEIL: It’s not my decision. It’s not that I find that I need them to do it. They know that they need to do it, would be a better way of putting it.

CLAIRE: Ok.

NEIL: Em..if left to my own devices, I just..well, from having a bad day or a couple of bad days, I wouldn’t do anything. They help. It is actual help like but..

CLAIRE: And like food shops and things? Do you go and do food shops together?

NEIL: Yeah - when Caroline's getting hers, she'll pick up something for me. But like I said, it's very little I'll have because I'd normally eat in Caroline's or at home it would be takeaways because I don't cook, I don't trust myself.

CLAIRE: Fine.

NEIL: Especially and that's another thing with the medication, I could forget – if I left something on, I'd forget. Like cooking appliances and things like that, I stay away from them. That's why takeaways and stuff like that, it's just easier.

CLAIRE: Yeah. And then, how many times do you do a food shop? Do you do just like a once a week shop or do you go a few times and get a few bits in…?

BARRY: Just bit by bit.

CLAIRE: Bit by bit. Physically walking – how far do you think you can physically walk before you have to stop?

BARRY: Well normally I'd stop, with my ankle, I'd say about the length of your corridor. For my ankle, all I have to do, there's wee – when I was in the cast, they showed me little exercises to do, just turning your ankle in little circles and I think it helps circulation as well. So I would stop and just do a wee bit like that and continue on. Obviously if I'm out and about if there's any seats and benches, I'd always take a wee break and sit down and have a little rest. With the gout, now that's completely different. A snail would beat me in a race. Em…the gout's terrible but luckily enough, it's not every day like the ankle.

CLAIRE: The last bit we have to do is just the physical assessment, ok? They're just movements ok? I do them, you see if you can copy them. That's it. There's only a few. We just do your lower limbs.

NEIL: What sorry, could you explain again?

CLAIRE: They're just movements I ask you to do. I do them and you see if you can copy them.

NEIL: Ok..

CLAIRE: It sounds odd. It's like Simon Says. So you stand there, I'll sneak round the back so you can see what my feet are doing?

CAROLINE: Do you need me to move?

CLAIRE: Oh you're fine, don't you worry. Ok, so it's just seeing if you can go up on to your toes?

NEIL: I can't do it on the left one. I can do it on that one? I can get the left one about half way up?

CLAIRE: Ok, is that…?

NEIL: It's too much pressure on the plate.

CLAIRE: That's fine. And let's just see if you can do a little dip in your knees?

NEIL: About that far?

CLAIRE: Yeah that's grand! And then seeing if you can pick up one foot –

NEIL: It would have to be my left foot.

CLAIRE: Yeah that's fine, the other way is then swapping it over but if you can't –

NEIL: No I can't, I can't..i couldn't put the pressure on that one.

CLAIRE: That is fine. That's you done. You have a seat. (*They sit*). That's you done.

CAROLINE: So what happens now?

CLAIRE: Basically this all gets typed up and this gets sent off to the DFC, the Department for Communities. They look at everything and they'll make a decision. And they'll be the ones that you hear back from.

CAROLINE: Can we get a copy of the report that you're sending?

CLAIRE: You can.

CAROLINE: Can we get a copy of it now or do we have to wait?

CLAIRE: You have to wait, and you have to put an application in with them.

Caroline: OK.

NEIL: How? With the…?

CLAIRE: The DFC.

NEIL: And do you have contact details?

CLAIRE: Yeah, you can just find them online, it's just the DFC.

CAROLINE: Yeah I'll get that, it's grand.

CLAIRE: So you get a copy of this, and we give this back to you as well –

NEIL: you can actually keep that because I can get it printed off again anytime.

CLAIRE: No it's no bother, I can just get it photocopied downstairs. It's up to you. It's your copy.

NEIL: Ok, maybe just photocopy it just in case.

CAROLINE: Em, Claire I'm a bit concerned that em, obviously this is going on what Neil has said. You know, it's the first time Neil's met you and he's the kind of person I know, he's presenting the best possible - because he doesn't want to put anybody out, the best part of himself. And, he has a mental illness.

CLAIRE: Mmm-hmm?

CAROLINE: And I'm a bit concerned that that report that's being typed up is based on what Neil has said, someone who has Schizo Effective disorder who is also alcohol-dependent, with no doctor present – do you know what I mean?

CLAIRE: I'm a healthcare professional.

CAROLINE: You're a healthcare professional. What trust do you work for?

CLAIRE: I-I-I work for Capita –

CAROLINE: Oh it's for Capita –

CLAIRE: So..

CAROLINE: Do you mind if I ask what your qualifications are?

CLAIRE: Eh, yeah..we're not allowed to say so if you want to, you can apply to Capita to find out our background –

CAROLINE: Oh, ok.

CLAIRE: But we're trained disability assessors for Capita, so that's the role that we work in now.

CAROLINE: Ok, that's grand then. Thank you very much.

CLAIRE: That is not a bother. Let me go and get a copy of this for you.