**Royal College of Occupational Therapists response to the Second Independent Review of the Personal Independence Payment Process (Northern Ireland) October 2020**

The focus for this call for evidence is on the following four points:

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## Summary

The Royal College of Occupational Therapists (RCOT) approached its members to provide feedback regarding the four points above during the Summer of 2020. The majority of responses we received have been from occupational therapists supporting claimants through the PIP process and they have shared information that claimants have passed onto them. We have also received some information from occupational therapists who act as assessors and this is included on pages 4 and 5. Most of the feedback has been critical, detailing inflexible assessment processes that place an undue burden on people with serious health conditions, resulting in exacerbations in health inequalities. The need for reasonable adjustments due to disability seems not to be applied to the process.

# How the assessment process is operating

## Complexity of process

For many claimants, the complexity of the Personal ndependence Process (PIP) process means it can be inaccessible. There are many steps involved which claimants are required to comply with and if they experience difficulty, it is easy to fall out of the system. For example, after they receive the request for the PIP application in the post, they are required to complete the assessment within two weeks and return to the appropriate department. They then wait to be called or to receive a letter for an assessment date, time and venue. Claimants are given appointment times and then requested to physically attend for their assessment. Some assessments are completed over the telephone and some via home visit but there appears to be no consistency to this. If a home visit is required, this needs to be requested by the claimant or someone supporting them. The claimant then waits for the decision with no definite time scale for this and current benefits can be affected during this period. If the claimant’s application is declined, they again must respond within a certain time scale for an appeal.

## Cancellations and delays

Appointments are being regularly cancelled often on the same day, leading to long delays in the process. This can add to already existing anxiety and paranoia. Some claimants worry excessively about upcoming appointments, only to have a cancellation and then go through the whole process again. Even when the process runs as planned there are long delays which can pause much-needed benefits.

## Difficulties for claimants with specific problems

The assessment process requires the ability to use the telephone which is not suitable for all new applicants such as those with learning, communication and interaction problems. The assessment form seems more designed for physical disability and therefore claimants can be penalised if unaware that they need to write around these questions to represent the impact of their problems. Those with a lack of family support or awareness of the process are disadvantaged and tend to be the most vulnerable. Support to complete the forms is not always available. If a claimant has good skills in one area, it appears to be used to indicate that they do not have other difficulties. Claimants who do not have access to services are disadvantaged as the lack of contact with services is interpreted as not having difficulties. Claimants on waiting lists are also disadvantaged as they cannot always provide evidence of their problems. Claimants with problems that will not change or will deteriorate such as Downs syndrome or dementia are put up for reassessment which can cause undue stress. Some potential claimants have literacy needs and cannot read the PIP application or the information provided, therefore do not complete the claim form. Others are unable to process the information due to cognitive deficits therefore cannot complete the steps required. Some potential claimants are unable to request assistance, advice or help to complete the PIP application due to communication difficulties, lack of confidence, anxiety, low mood, thought disorder and therefore do not complete the claim forms. There is also confusion about whether claimants can have someone in the assessment with them to speak for them, represent them or act as a second witness to the assessment.

## Final report

Many claimants report that the assessment that takes place is not reflected in the final report. Detailed information is left out or information in the report was not mentioned in the assessment. Claimants often report that the assessors don’t seem to be aware of mental health issues but will make judgements, sometimes based on their observations in sessions, giving a lot of weight to items such as eye contact or how fidgety or restless someone is. (NB, occupational therapists acting as assessors have good mental health skills and are trained at undergraduate level equally across physical and mental health so we would not expect this to be the case with them). Claimants report that the assessor only writes down parts of the answers that are given or items are put in the report that the claimant says they did not say. Finally, different assessors’ approach and decisions can appear to be inconsistent about who gets the benefit and who doesn’t.

# Claimants experience of taking part in the process

## Emotional impact

Many claimants say their experience is “horrendous”. Many aspects of the process exacerbate anxiety and depression unnecessarily. The stress leads to ongoing worries about when the next review will be. In addition, claimants experience great concerns about their financial and housing situations during and after the assessment. Some potential claimants decline to complete the forms or appeal process due to avoidance of the stress/impact on mental health, and their financial situation can be seriously compromised. Some claimants have stated that if they are unsuccessful in their claim they will “kill themselves” and require an increase in input from mental health services. Others experience an increase in stress and a decline in their mental health as a result of their claim taking too long, or a change in their circumstances affecting the amount they receive. Some become reluctant to apply for PIPs due to fear of having their benefits stopped altogether, reporting this fear is based on peers’ experience. Some claimants report feeling suicidal after reading the assessors review of their difficulties, especially when they feel it is not accurate. Others worry about giving personal information over the phone and are unaware that there is some support available through voluntary organisations. This means those most in need drop out.  Many claimants also get angry at their treatment, especially when asked to perform what can feel like meaningless tasks during the assessment. For example, being asked to climb in and out of the bath when they don’t usually use the bath, or being asked to reach inside their pocket, only to be later told there are jobs available that they can do if they can complete this action. All of the above can cause great financial problems and unnecessary poverty for some potential and actual claimants who report feeling “like second class citizens or criminals”. Many claimants report feeling shame and guilt requesting this benefit.

*Experience for specific groups*

## Claimants receiving palliative care

The issue of special circumstances for claimants with a terminal illness is extremely difficult. Many claimants have a terminal diagnosis but their prognosis is beyond 6 months and clinical staff are not comfortable filling out the DS1500 stating that they have < 6 months to live. Being forced to give a prognosis for a benefit application is very difficult for all concerned. The psychological impact of the PIP assessment process when someone has a life-limiting illness is also hard. Claimants report that when they describe their problems to the assessor, they do not feel the assessor comprehends the sheer impact of the condition; it is very difficult to describe to a stranger the impact of a devastating illness on an individual’s life.

## Claimants with fatigue and pain

The symptoms of fatigue are very difficult to articulate to assessors. Claimants report that they find it hard to describe its impact because they can complete a task but the effect of residual fatigue can be felt for hours or days after. People with fatigue and pain are encouraged to prioritise tasks and break tasks down over the course of a day. They often have to choose one task over another to manage fatigue levels and this may not be considered by the assessor if tasks are completed or delegated.   The impact of breathlessness is similar but the symptoms are often more apparent during the task. Also, claimants may be on different types of pain relief which can alleviate pain and potentially allow for more function, but which in turn impact on their fatigue, cognitive functioning and lethargy levels.

## Claimants with Autism Spectrum Disorder (ASD)

In Adult Autism Spectrum Disorder Services many claimants report significant difficulties with the current PIP assessment processes. The main difficulty is that ASD is so multifaceted and that those with ASD without a learning disability may often mask underlying deficits (hidden disabilities) which may significantly impact on adaptive function. Individuals with ASD who are deemed to be high functioning with significant verbal ability, may still have significant deficits in performance/executive function and may struggle with basic daily living tasks. Only a very small percentage (15%) of those with ASD successfully sustain employment despite having high-level knowledge and skills.

# Perceptions of healthcare professionals involved in carrying out the assessments

Occupational therapists can act as assessors for the PIP. RCOT believe they are well placed to do this with their training in functional ability, independence levels across both mental and physical health and their experience working with specific groups such as people with fatigue and pain. They feel that unfortunately, a common myth exists that the assessors get paid a bonus for removing someone from benefits, which is not true. However, it has widespread traction and there are reports of whole services and organisations which believe this. Assessors feel they work hard to make claimants feel at ease during the assessments and that occupational therapists are particularly good at this. As assessors, they received additional training from condition-specific charities such as the MS Society to help them understand the impact these conditions have on everyday function. However, despite the skills mentioned above that the occupational therapists bring to this role, they have two main challenges:

Assessment time limits; The assessor's experience of only being allowed 45 minutes to do a home visit assessment is difficult particularly for those with multiple complex conditions who live by themselves. Some claimants will have, for example, twenty different medications and seven different health conditions. The assessor has to go through each, look at the dosage and check it’s the same amount on the records. The claimant usually wants to talk about each health condition and how it affects them in turn. Additionally, for some people, the assessor may have been the only person they have seen for some time.

Inability to deliver interventions; As assessors, frequently they would like to mention something to a claimant that may help them such as a piece of equipment to buy. However, as they are only there to carry out an assessment and not any type of interventions, they are not allowed to do this. This reduces job satisfaction and means the claimant loses an opportunity for some expert advice.

# How effectively further evidence is being used to assist in correct claim decisions

## Helpful to have this evidence

Having additional information can be an important part of the process especially if the claimant is only seen for a relatively short amount of time. Having another professional’s opinion, even a GP report with their medincines, gives assessors ideas in advance about what questions to ask.

For example, with mental health, a claimant may have severe depression but has been able to get up, washed and dressed to attend their assessment and engage in the process. This will count against them in the PIP assessment as it is taken as an indication of the level of severity of illness. But the current process makes no indication of what they went through to get up, washed and dressed that day and assessors don’t see what it took them to do this. It seems unfair to base an assessment on how someone presents on one particular day.

Further evidence is crucial. A letter from a Community Psychiatric Nurse or psychiatrist can help assessors understand more of what the person struggles with. Some of the mental health assessment seems to rely on the experience and empathy of the individual assessor. This means some of the claimants can be scored more negatively if seen by a particular assessor because others have more understanding of how much effort a claimant may have made for the assessment.

## Amount of evidence provided

When claimants do provide further evidence, sometimes it is too much information. Assessors are given 20 minutes to read additional information and if someone has submitted, for example, 180 pages is too much information to read. Assessors are supposed to check each item for the date, who it’s from and a brief description of the evidence. It can take up to three hours to read this and assessors have to approach a manager to get the additional time agreed. If claimants could submit shorter, up to date information it would help the assessor. Additional information can also be supplied face to face. Occupational therapists have attended appointments to support vulnerable claimants who did not have friends or family to support them. Assessors can find this extremely useful to have the occupational therapist there as they could add their insights to the process.

## Being asked to provide additional evidence

As useful as this evidence is, this has an impact on the workload of other services when trying to provide evidence for claimants that already exists and, in some cases, is already held by assessors. Claimants sometimes want to be referred to services just to have evidence of their difficulties leading to unnecessary referrals. Occupational therapists are approached to write documents to support the appeal process and report that despite providing information, the psychological and mental health information they provide is often not taken into consideration. Further evidence seems to be rarely sought routinely from mental health services, unless the claimant has requested assistance with this from their GP, consultant psychiatrist or keyworker. It feels like the responsibility is left with the claimant to gather further evidence and present this to the PIP assessors. Therefore, the gathering of further information is reliant on the claimant having the functional abilities to do this. Information that is shared is sometimes not reviewed, although on appeal this information is enough to either reinstate or award benefits.

## Appeals

Appeals can be lengthy, sometimes up to nine months and then claimants often get their payments reinstated. Groups which lose out are claimants with additional learning needs and mental health problems who don’t seem to get the right assessment. The appeals process is difficult and claimants with mental health conditions will report that they lack the motivation or confidence to appeal decisions and sometimes will just accept them, as the don’t have the energy for the fight. For example, claimants with severe and enduring mental illness sometimes have their benefits stopped because they have not provided adequate information on the forms and did not attend a review or appeal meetings. In some case where families have got involved, they can advise of the claimants’ diagnosis, provide contact names and addresses of the mental health service and psychiatrist providing care but nobody is contacted prior to the benefit being stopped.

Claimants experience having to appeal decisions when the evidence is clear about the difficulties faced and information previously sent seems to have been ignored. There are problems with not taking forward previous information held by the person from Disability Living Allowance applications. Many claimants do not understand that the tribunal process for appeal is a legal process and that they need support to be able to engage in this fairly to represent their problems.

Finally, after appeals, payments are often backdated due to delays and this can result in very large sums of money being paid to claimants who cannot manage money well or have addiction issues. The resulting chaos can interrupt the occupational therapy process.

**Acknowledgements**

This submission would not have been possible without the expert views of occupational therapists in Northern Ireland both as assessors and as supporters of claimants going through the process. RCOT would like to thank everyone who gave their time freely to share their views and we hope this helps drive the necessary change to improve the process for all parties involved.

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