

## WSUN's Strategic Response to "PIP Detailed Designed Criteria"

### Forward

The Wiltshire and Swindon Users' Network (WSUN) is a user-controlled organisation that meets the Department of Health "Design Criteria" for an established User Led Organisation (ULO). WSUN supports people who come with the experience of having physical or sensory impairments, using mental health services, being an older person, or having a range of learning difficulties. (Hereafter referred to as marginalised groups, this will also apply to the other 8 Equality Characteristics. As stated in the Single Equality Act 2010. This Act is central to WSUN's basic principles' in how we support our members to become involved to develop ideas to shape services such as those proposed in the emerging; Welfare Reform, Health, Social Care and Community Partnerships and until recently WSUN was also working closely with Wiltshire and Swindon Police Equality Unit.

WSUN has a joint role in educating and learning from the wider society on how to meet all our diversely rich and genuine needs, at the point of all service delivery, whether that comes within our own communities or from the voluntary, private and public sectors'.

WSUN can to set up Focus Groups to undertake and scrutinise plans, in the role as "a critical friend". Working in this way we have a proven track record of skilful facilitation and supporting the development of a mutual understanding of every ones issues. With the aim of collating empirical experiences and evidence together to co-produce Action Plans. That are then jointly agreed as Equality Impact Assessment criteria, that meet the tests of both, "Proportionality and Legitimate Aims", in accordance with the Single Equality Act 2010.

Using these skills WSUN aims to support, the true participation and engagement of Marginalised Groups to have their say. In how society is shaping and developing new policy directions. WSUN is supporting people to move along the road to becoming more socially inclusive, of disabled people understanding what, it means to be a “Full Citizen” with rights and responsibilities.

WSUN has successfully, (from the 1<sup>st</sup> August 2010) taken on the “Host” role and responsibility for the Wiltshire LINK (locally known as “Wiltshire Involvement Network – WIN” and now co-produces this function with Age UK Wiltshire.

WSUN believes, and is totally committed to the vision and values of social inclusion, (including Equality and Human Rights for all). Ensuring and promoting Dignity and Respect for all in our local communities.

There is a need to ensure ULOs are supported appropriately with continual funding to ensure this vision becomes a “true reality for all,” not just a few.

In terms of increasing peoples' capacity: **“to get around.”** WSUN has developed a very successful **award winning project!** Called, the “Wiltshire Independent Travel Scheme” (WITS). WITS is an independent project offering initial travel support to individuals who would like to travel independently on public transport for **work**, to meet friends, for college or training.

After meeting the person for the first time, we design an individual programme of support depending on their skills and needs.

A travel supporter will accompany the person on their journey until they become confident. WITS has successfully worked with people and developed techniques to enhance their individuals skills like; **planning a journey, road safety, telling the time, using money or a bus pass and help to build confidence.**

The only cost to the individual are any bus or train fares although where possible we will assist people to apply for disabled person passes.

**Many of the people who use the WITS project find that they not only become independent travellers but the skills and confidence they gain opens up further opportunities.**

## Introduction

WSUN support the Government's ambition and principle of creating a benefit (in the form of PIP) to support disabled people overcome the barriers they face to leading full and independent lives. And yet, we do not believe that the Government's approach to DLA reform thus far does enough to achieve this aim. We believe that the basis for the assessment process is centred too much on the medical model of disability –focusing only on an individual's inability as a result of their "physical, mental or cognitive impairment with disabling effects". As a consequence, it will only show a small part of the picture of the real barriers and disability-related costs disabled people and people with mental health conditions face, day in, day out.

WSUN's preferred approach is an assessment that genuinely seeks to capture the barriers that a disabled person faces in their everyday life, and what effect these have on their capability for choice and control, participation and independence. With this in mind, set out below is an alternative vision for.

There are a variety of ways as to how best to capture information about the barriers a disabled person faces, and how they might be entitled to additional support from PIP. We recommend the trial of an approach that:-

- **Takes greater account of the social model of disability.**  
By accounting for the social, practical and environmental barriers – and disability costs that come with these – as well as how an individual manages or copes with their condition or impairment;
- **Is co-produced with the claimant, 'not done 'to' them.**  
WSUN harbour serious concerns of the assessment for PIP making the same mistakes as those pointed out by Malcolm Harrington in his review of the WCA – that it is "impersonal" and "mechanistic" and "lacks communication" between the parties involved.

- WSUN strongly believe that the PIP assessment needs to take the form of a conversation between the prospective recipient and the assessor, and believe there are very valuable lessons to be learned from person-centred planning, transition plans, and support plans used in Personal Budgets and Direct Payments.

### **PIP should be designed to helping disabled people overcome the barriers they face.**

People facing significant external barriers, which could be reduced or removed by intervention from services (housing, for example, or Motability) are passported onto the relevant services. This already occurs in other assessments, and would be hugely beneficial to both the lives of disabled people receiving PIP, but, we believe, also to Government as the removal of barriers and costs would reduce the need for PIP, and ultimately lead to lower spending on the benefit over the long term.

- **Collecting evidence of barriers**

Consider the need for an early collection of evidence that would be relevant and beneficial to both the prospective recipient and the assessor. The recipient – having newly applied for PIP or having been informed of a forthcoming assessment as result of being migrated from DLA to PIP – undergoes an initial preparation stage during which they would be able to submit existing evidence that would help to highlight the barriers to independence and participation that they face. Such evidence could take the form of a transition plan, a support plan (for those who receive a Personal Budget), a care plan, evidence from their GP (although, many GPs charge for this service) or other forms. None of these would be obligatory, but would help highlight the barriers they face, the needs they face, and the support systems – or lack thereof – that they have in place.

Such evidence could then be used as the basis for conversation between the assessor and the prospective recipient when they get to the assessment stage. The benefits of including this stage would be two-fold: it would help the claimant prepare for the assessment; and would

also potentially save costs by making the assessment itself more time efficient as many of the barriers have already been brought to the assessor's attention. It is important to note that a prospective recipient who does not – or is unable to – provide such evidence would not be disadvantaged; simply that the assessment itself would take a little longer in order to identify from scratch where the barriers to participation and independence arise in their life.

Finally, the introduction of a proper preparation stage would allow the recipient to access advocacy support such as an individual or a group; peer support network; formal, professional, paid, legal or citizen advocacy; a support or key worker; friend, neighbour or family member, or anyone else.

**WSUN recommend that the DWP directly inform the prospective recipient – via the letter that informs an existing DLA claimant of a future PIP assessment, or when contacted by a new PIP claimant – of the option of finding a support figure with whom they can undergo the assessment process.**

**A more multidimensional assessment that places greater emphasis on the social model of disability.**

As the evidence, examples and arguments set out in this paper serve to demonstrate, the principles underlying the assessment. The activities and descriptors contained within need to be configured if the test for PIP is to enable the Government to achieve its objectives of supporting disabled people to overcome the barriers they face to leading full and independent lives. Ensuring that the support is focused on those with the greatest barriers. To produce an assessment that protects and supports people who have the greatest need and would benefit from additional support.



- terms of condition management  
in other words, how the individual manages their impairment or condition on a day-to-day basis, what their coping strategies are and what support they get from other people (if any);

**Consider the external barriers – be these social, practical, environmental or other – that prevent the individual from exercising choice and control, and leading a full and independent life.**

To do this, we believe the assessment needs to combine a points-based descriptor, approach *and* that of a broader, more qualitative approach similar to that used in the assessments for Personal Budgets.

**WSUN would therefore recommend, a more multidimensional, social model-based approach to assessing eligibility for PIP. This will seek to capture the following information via a more social model based, multi-dimensional assessment. However, further development, testing and trialling are needed to improve and refine the criteria suggested.)**

#### **Details of general circumstances**

(Name, address, DOB, NI number, etc.). In addition to more generic personal and contact details, this part could also be designed to capture the individual's living situation. For example whether they live alone or with family, friends, partner, etc. Also whether they have someone who looks after them (formally or informally).

This would help capture information about the prospective recipient's living status and any existing formal/informal support networks. Which WSUN knows has a real impact upon the barriers and disability-related costs that a disabled person incurs.

#### **Information about current difficulties and issues they are experiencing:**

This would allow the prospective recipient to explain why they have applied for PIP. A 'free-text box', filled in by the assessor and the claimant could help capture vital information, or/"life story" this will allow

the individual recipient the barriers they encounter in their everyday life. This would help the assessor identify whether they would benefit from additional support and other areas to be discussed later in the assessment. This kind of information is already captured in Self Assessment Questionnaires (SAQs), and there is no reason why this could not be included in a future PIP assessment.

WSUN are concerned that, in their current form, the claim form and reassessment process will result in disabled people not being awarded PIP, even when they are clearly entitled to it, at huge personal cost to disabled people and their families. It will also inevitably lead to greater costs in time and money for both the DWP and advice agencies, in escalating demands for advice and appeals.

## Answers to Consultation Questions

### Chapter 3 questions - Eligibility

Q1. Does our approach on the linking rules support the policy intention of providing continued support to those with a long term conditions which can fluctuate or deteriorate in the most reasonable and effective way? If you don't agree, please tell us why and what an alternative approach could be?

Yes, with the proviso that the deterioration and 'reasonableness' in fluctuation conditions complies with a 'reasonable test' in the Single Equality Act. The individual concerned has the opportunity to challenge or provide additional evidence to support their claim.

WSUN is concerned that anyone previously on DLA or PIP but has recovered would be able to reclaim immediately if the same condition recurred but must wait 3 months to claim for any new condition

Q2. Are there specific matters regarding this age group that would warrant a different approach?

As long as the process outlined in the case study relating to question 2 is followed and time frames are realistic. Then the assessment transition appears to be sufficient.

However, if the assessment differs from that of the young adult who has just come of age, ie just turned 18 years old. There needs to be a process for mediation to come to agreement. (Bearing in mind the young adults will have the legal right, but the parents views need to be taken into consideration.

Q3. Do you think we should do something different from our proposed approach to ensure transition at age 16 works effectively?

No, as long as both parties are consulted about the transition and there is agreement. Again, mediation may need to be used, as question 2.

Q4. Do you agree that it is sensible to move towards a habitual residence test to simplify the claiming process by aligning with other benefits?

Yes in principal however, there is evidence to suggest that some residents do benefit going to a warmer climate for part of the year, and supporting their mental well being. But perhaps they should be paid on a reduced rate.

Q5. Do you think a requirement that a claimant must have been present in Great Britain for two years out of the previous three years is reasonable in order to demonstrate a long standing affiliation to Great Britain? Would a longer period be appropriate? And if so what do you think that longer period should be and why?

The two year period is 'reasonable' being compliant with the Single Equality Act. WSUN does not believe it should be any longer as this might have a detrimental effect on people's health and well being.

Q6. Do you think that serving members of Her Majesty's Forces and their families should be treated as habitually resident in Great Britain when serving and stationed abroad?



Yes, because it is mandatory and family members should still get that entitlement.

Q7. Is the period of four weeks temporary absence from Great Britain sufficient? If no – why do you think the absence should be longer? And what do you think that longer period should be (and why)?

Yes, unless the individual can show sufficient grounds as to why they need to be away. (For example, if they were due back during the four week period, but fell ill and had to remain in an overseas hospital. Therefore this circumstance is not within their control, because of flight delays.

Q8. Is six months temporary absence for medical treatment sufficient? If no – please explain why you think this period should be extended. And to what period?

WSUN believes this has to be considered on a case by case basis. In terms of extended absence due to a longer holiday would be sufficient grounds to reduce it as per proposal. There may be circumstances that this may need to be looked at. But WSUN believes the emphasis for making the case for an extension for the four weeks under extenuating circumstances need to be made by the claimant on their return with appropriate evidence to support this.

Q9. Are there any other circumstances when you think the temporary absence period should be longer?

Yes, but with the exception of If you are not a British National and need to attend to a family situation abroad, but you are still entitled to claim benefits in this country because you have contributed to our taxes. Again this would then meet the 'reasonable tests' under the Single Equality Act. This list is not exclusive, but would need to be considered on a case to case basis.

Generally the four week rule should apply.

## Chapter 4 questions – Payability of Benefit

Q10. Our approach to people over the upper age limit is designed to strike the right balance between claimants' needs and our intention to make Personal Independence Payment affordable and sustainable in the future. Do you agree our approach achieves those aims? If you disagree, please tell us what approach would achieve the right place.

Yes under 4.2.

However, under component 4; this may eliminate people who have acquired mobility impairments later on in life which can lead to greater isolation. Some exemption rules need to apply in extreme cases. Where this can be demonstrated and evidenced that this will directly affect health and well being. But WSUN understands the need to appropriately align with the Attendance Allowance with regard to the mobility component.

4.4. There needs to be further clarification on what is meant in 4.2. This ruling will potentially restrict a lot of people with fluctuating conditions and this statement is generally quite confusing in its content. Further clarification for a full and comprehensive answer needs to be restructured. As potentially there are a lot of implications if WSUN have understood your intention correctly.

Q11. Do you have any views on our proposals to take forward to Personal Independence Payment the approach taken by DLA and AA in relation to residency in care homes and in-patient care in hospitals?

WSUN has concerns about individuals who have higher purchase agreements for pieces of equipment purchased as an assessed need through the private sector. This particularly refers to 'self funders' under the social care eligibility financial criteria. Therefore if they are in hospital or residential care the funding will stop and they will not be able to continue pay for them.

Q12. Have we correctly identified that there would be duplication of funding if we continued to pay Personal Independence Payment while someone is in prison or legal detention?

WSUN has no comment to make on this issue as we have no evidence or knowledge of the judiciary so cannot agree or disagree with this statement or your intention at this stage.

Q13. Do you agree that Personal Independence Payment should carry on in payment for 28 days to allow disabled individuals to settle outstanding disability related costs? If not, why not? What alternative period do you think we should consider.

Yes, but in some cases it may need to be extended with regards to self funders and financial agreements entered into until those agreements come to their natural end.

Q14. Do you agree that two periods of imprisonment should link if there has been a gap of less than one year? If you disagree that periods of imprisonment should link please tell us why. If you agree that they should link but think it should cover a different period please suggest an alternative period.

WSUN has no comment to make on this issue as we have no evidence or knowledge of the judiciary so cannot agree or disagree with this statement or your intention at this stage.

## Chapter 5 questions – Reassessing existing DLA claims

Q. 15 There will be limited appeal rights against the decision to terminate DLA and safeguards will ensure that people who genuinely were not able to claim Personal Independence Payment within the time limits will be able to reengage with the claiming process without penalty. Is this a fair and proportionate approach to ensure people engage with the claiming process?

WSUN believes this complies with the Single Equality Act 2010. If implemented properly it will be fair and proportionate but “needs to consider its definition of limited appeal rights and terminated safe guards”. Making sure that the most disadvantaged are given more time to go through the appeal process accordingly. (For example somebody with severe learning difficulties, dementia, mental health or other cogitative conditions may need to consult with specialist services. To gather the evidence or require an advocate to be present. This would be in WSUN’s view an “appropriate and necessarily adjustment”.

Q16. Do our plans and timetable to reassess people for Personal Independence Payment appear sensible and reasonable? If not, what changes do you think we should consider introducing?

Given the numbers of people that need to be reassessed WSUN does not believe that the most extreme conditions the timetable will not be long enough. Some consideration needs to be given to the time frame for this to occur and consideration given to complex cases and communication difficulties. (For example), people with non verbal communication, British Sign Language Users, which may take considerably longer than you time frame would allow. Therefore WSUN can for see a great deal of anxiety for the claimant.

Q17. We intend to build a process to help us indentify claimants who may need additional help to claim, for example those with learning difficulties or mental health problems who do not have an appointee. Although the process will not be subject to regulations, we would be grateful for any views on this proposal and how best to identify those people who need additional support from the Department or from other organisations.

WSUN’s guidance should be sought by local ULOs who may know the individual, and with the **right funding** would facilitate and support their understanding and, or act an “Appropriate Advocate”. However, “The Mental Capacity Act (2005)” should always be the baseline to establish the “Lack of Capacity Assessment” process.

Q18. Our plans include procedures and rules to ensure that everyone invited to claim Personal Independence Payment will be repeatedly reminded before their benefit is first suspended and then terminated. Are there any other matters we should consider to ensure that everyone currently on DLA who may be entitled to claim Personal Independence Payment does so, and within reasonable time limits?

WSUN believes this is fine as a general principal. However, a variety of means and different accessible formats need to be used in order to make that initial contact and follow up if necessary. For example (do not assume that someone who is blind has a support worker to read the information. Or a person with learning difficulties can read a letter without support.)

### **Chapter 8 questions – Residence and past presence tests**

Q19. Do you think claimants should have to satisfy a habitual test instead of the ordinary resident test?

WSUN agrees in general with habitual test, with the exemption serving Her Majesty's Armed Forces.

Q20. Do you think a requirement that a claimant must have been present in Great Britain for two years out of the previous three years is reasonable in order to demonstrate a sufficient affiliation to Great Britain? Would a longer period be more appropriate?

WSUN believes this is reasonable.

Q21. Do you think that children should have to satisfy a shorter past presence test? What would be a reasonable test for children?

WSUN agrees in principal.

Q22. Do you think that serving members of Her Majesty's Forces and their families should not be expected to be habitually resident in Great Britain?



Yes. However, If the child is the recipient of the PIP and the parent or the guardian is a serving member of the armed forces, then the previous exemption in question

Q23. Is the period of four weeks temporary absence from Great Britain sufficient? If no – why do you think the absence should be longer?

This question needs to be clarified further.

Anyone in receipt of DLA or PIP will be allowed to spend only 4 weeks abroad before payment terminates. It does not make clear whether this is allowed just once a year or whether someone could travel repeatedly between UK and abroad as long as they didn't exceed 4 weeks abroad at any one time.

Q24. Is six months temporary absence for medical treatment sufficient? If no please explain why you think this period should be extended.

Yes in general. However, there may be certain conditions that medical evidence needs to be sort. If it is unsafe for the person to travel back during that period. WSUN believes these needs to be properly medically evidenced. This should be done by a case by case basis.

Q25. Are there any other circumstances when you think the temporary absence period should be longer for instance for people over state pension age?

WSUN believes in this case that individuals of state pension age, need to apply for (reconsideration/decision maker) before they wish to travel. There may well be strong family ties abroad. Needs to apply with European Union regulations.

## Chapter 9 questions – Impact assessment

Q26. What impact could our proposals have on the different equality groups?

Q27. What else should we consider when developing our policy?

Q28. We have indicated areas we do not have information to consider the impact on protected groups. We would be interested in suggestions on where we can find robust evidence that we can use.

In terms of quality impact assessment questions 26 to 28 the following should apply

### Race and Religious Belief

- DWP have already acknowledged you do not collect data on this. In order to make an accurate assessment on the impact. This information needs to be collected. However, WSUN can foresee that these groups may be adversely affected when it comes to family ties and observing religious holidays with their families living overseas. For example Ramadan

Some “proportionate adjustment” is made to consider these issues. A policy needs to be developed in order to give decision guidance on these issues. Training on the Single Equality Act 2010 should be mandatory for all decision makers.

### Disability

- With regard to this issue WSUN believes that you may get a number of disabled people organisations using the proportionality and “reasonable adjustment” to build a case for reconsideration or appeal.

Again policy guidance is essential, so this applied across the board. For example if you lived in a Northern town it should be applied in the same way as it is in Cornwall.

WSUN can see no other equality impact needs for the other groups at this time. But as data and information from decision makers is

collected, this need to be monitored and adjusted accordingly as necessary.

### **WSUN's Additional Questions for Consideration in the Implementation of PIP:-**

- Will people on Enhanced Mobility Component lose their Motability vehicle after 28 days in hospital?
- If a person is in hospital beyond 28 days or is moved to a care home, and they are funded by the NHS or local authority, will the person continue to receive their PIP component? However, will the same rules apply if the person moves to a care home or in private health services and therefore a self funder? Will they be entitled to PIP?
- Will both rates qualify for Carers Allowance?
- Will any PIP entitlements to the future "Universal Credit" disability premiums and enhanced rate of qualify for enhanced disability premiums?
- Will PIP also form an entitlement to extra Pension Credit allowance and the Carers Credit?
- Will the enhanced mobility component qualify for the Motability Scheme?
- Is there intention for the Department of Transport to consult about Blue Badge eligibility at some stage?