Response to Second Draft of Assessment Criteria for Personal Independence Payment (PIP), and the Proposed Thresholds

From The Mental Health Action Group, Derby

Introduction

The Mental Health Action Group (MHAG) is a service-user led organisation based in Derby City and covering the whole of Southern Derbyshire. We have already commented on the previous two drafts of PIP, and now comment on the latest consultation documents which give greater detail on the assessment criteria, and latterly the proposed assessment thresholds.

We still have serious concerns about the position of people with mental health problems. Even though we are gratified to see that changes have been made to reflect our comments on the previous paper, we still feel that mental illness is not given sufficient weight in the new draft, and that many will struggle to meet the assessment criteria.

We have made a number of observations and comments below which we hope you will consider in the lead up to your final proposals.

Para 4.14

There still seems to be some confusion over what is meant by a "fluctuating condition". Illnesses such as Bi-polar Disorder, Schizophrenia and Anxiety Disorder and many forms of Depression fall into this description. All of them can be treated with varying degrees of success by medication and therapy. However, it is the nature of these illnesses that even with treatment, they can have a wide distribution of effect on the individual. This can vary from short and acute bursts of incapacity to longer and extremely debilitating periods. Sometimes this may even mean permanent disability.

These instances can come on without warning and can lead to admission to hospital for acute care. The statement by Government that it, "…does not believe that support needs arising from short, acute periods of impairment should not be met by this benefit", therefore begs the question; "What benefit *will* support such people?"

Our suggestion is that the guidelines should be changed to reflect the individual situation, and that assessors need to balance their recommendation on medical advice and opinion. Short acute episodes can be very debilitating, and require a long recovery. There is no way of generalising in this area. Alternatively, a separate benefit should be made available to those who suffer in this way, so that they are not disadvantaged. The risk is that many people will remain in acute care far longer, and at

greater cost to the tax-payer, because they will be unable to cope in the community without their benefit payment.

Para 4.24

Please do not forget that the "Engaging Socially" activity as defined in your draft does not take into account the following:

- Dual diagnosis. IE, where a person has both a physical and a mental disability. Which takes precedence is unclear; we believe that both should be taken into account equally.
- Some physically disabled people suffer from mental health problems because of their disability, even though this may not be diagnosed.
- Many people with mental health problems find their ability to "move around" is impaired because their mental state can affect their physical health.

Although we applaud the attempt to identify mental health issues specifically, it would be a step in the right direction to acknowledge that mind and body are intimately linked, and that one has an effect on the other. Therefore, they cannot be wholly separated.

Para 4.31

A general comment on the use of the words "assistance" and "prompting": is it worth acknowledging in specific terms that assisting and prompting can include carers as well as health professionals? The role of carers is very important in all disabilities, not just mental illness; however, the taking of medication is an area in which carers have a prominent role. This is especially true of those conditions where the "patient" can cease taking medication because they feel "well", or where their condition causes them to become confused.

There should be a distinction between what is meant by "continual" support and care, and "continuous" support and care. Continual means regular and reliable, whereas continuous means all the time.

Activity 8 "Engaging Socially"

A general comment: the third bullet point in this section refers to those who may need support to understand issues such as body language etc. These issues are most common in those with learning difference or personality disorder, as well as autism or Asperger's Syndrome. These are classed more as neurological disorders than mental illnesses. However, many people with these conditions will suffer mental distress as a result of their anxiety.

We are pleased to see that the definition of "Overwhelming Psychological Distress" has been modified. Episodes of anxiety and panic can strike suddenly and without warning, but their subsequent effects may be short-lived. This does not mean they should be treated more lightly, as the experience is extreme and very real to the sufferer.

Also, there may be cases where people have apparently recovered, only to suffer "flashback" panic attacks later, and the damage is more profound. Assessors should consult patient notes on this issue.

The same comments apply to **Activity 10.** Many people feel trapped inside their own place of residence by their illness, or the fear of its effects. This can also be a fluctuating condition; some may find they can take a journey if accompanied by a trusted person, but this will depend on their state of mind at the time.

Assessors need to take into account the effect of phobias on some people.

Other Issues

We are concerned that some people with severe disabilities may lose their "Severe Disability Premium" as the result of poor assessment, and that medical evidence solely be used to determine whether someone should receive this payment. Also, evidence from support and care workers should support this premium.

Thought must be given to using Care Plans as evidence, as these should give an accurate current picture of a person's disability and needs. However, all assessments, especially those for people with fluctuating conditions, must be based on the "worst day" scenario, ie, their need when at their lowest ebb. Assessments must not be based on "good news" evidence which has been "cherry-picked" from notes and care plans, because it supports the notion that the person is not entitled to benefit.

We understand that assessments will be carried out by a contracted company or companies. We therefore urge that:

- All contractors must apply the same standards and approach across the board, and be regularly monitored for quality and reliability.
- All assessors must be fully trained in awareness for all disability groups, including mental health problems.
- The lead-times for assessment must be longer, ie, people must be given more time to prepare before completing forms and attending interviews, and be able to obtain support and advocacy if they need it. We suggest 6 weeks minimum.

- A full and open leaflet must be sent with any assessment notice, written in Plain English and explaining exactly what the process will be, and the individual's rights and responsibilities.
- Lead times for appeals must be shortened to a maximum of 3 months
- To avoid financial hardship and anxiety. In cases of clear error, thought should be given to compensation for victims of assessment and loss of benefit.
- We are aware that Government contracts cannot include penalty clauses. However, there should be incentive payments for contractors whose assessments are deemed to be accurate, ie, the fewest number of successful appeals.

Proposed Draft Descriptor Weightings

We are pleased to see the weightings at last, although we do not necessary agree with them all. However, it would have been even better if we had some indication of the thresholds to qualify for PIP (however, we have now received these). We have formed the impression that the DWP will simply "draw a line" under what they can afford overall, and that some people, however disabled, will drop below that line because of an arbitrary financial limit.

We hope that the qualitative part of the assessment will be thorough, searching and accurate, and ***make full use of medical notes*** where appropriate. How this will be achieved is an important point; we urge that medical information be sought from the very beginning, and taken fully into account in all assessments, not just called for as an afterthought, or to provide additional evidence during an appeal. Let's get the right assessment made first time. This will reduce stress and anxiety and ensure fairness and no unnecessary loss of benefit.

The DWP needs to be aware of the "Catch 22" nature of aids and appliances. Often in the past, DLA has helped people obtain, maintain and use such equipment, and there is no doubt that this technology is very helpful in enabling people to lead fulfilling lives. However, this only covers the physical aids. There are many other areas where disability can have an adverse effect on quality of life. By claiming that a person no longer needs, say, the mobility aspect of PIP due to their use of such aids can lead to a significant loss of criteria points overall, and penalise them for being disabled!

Perhaps a better way of assessing people would be to ask the question, "would this person be able to lead a full and active life without the aid or appliance?" If the answer is "no", then we must not penalise that person in any way.

Draft Assessment Criteria

We list below those assessment criteria which we believe will impact on people with a mental health issue and why.

Activity		Descriptor	Reason
1. Preparing food and drink	D	Needs prompting to either prepare or cook a simple meal	Severe depression can lead to complete lack of motivation. This also applies to people with eating disorders
2. Taking Nutrition	D	Needs prompting to take nutrition	As above.
3. Managing therapy or monitoring a health condition	B-F	Needs supervision, prompting or assistance to manage medication and or therapy	People with mental health problems can often lack the motivation to maintain their programmes. Also, the medication itself can have side-effects that cause confusion or lack of cognitive skills. Supervision is often carried out by carers.
4. Bathing and Grooming	C	Needs prompting to groom	As above.
6. Dressing and undressing	C	Needs prompting etc.	When people are in mental distress they often become house-bound for long periods and do not bother to attend to dress or appearance. This can lead to a spiral of self-neglect, with consequent health problems.
7. Communicating	C-G	Various	Mental distress can lead to people being unable to process written information or understand oral

			communication. This can also be a side effect of medication. They often rely on carers or advocates to help with meeting others and making decisions.
8. Engaging socially	B/C	Needs prompting or social support to engage socially	As above.
8. Engaging socially	D	Cannot engage socially	This is a key aspect of mental distress and must be given due weight. We think it should score 12, not 8.
9. Making financial decisions	B-D	Needs prompting to make financial decisions, or cannot make financial decisions at all.	This is another area where people with mental health problems are very vulnerable and need help to ensure they can manage their money properly. For "Cannot make any financial decisions at all", the score should be at least 8.
10. Planning and following a journey	B	Needs prompting for all journeys to avoid overwhelming psychological distress to the individual.	Score should be higher at 6 to reflect the importance of social inclusion.
Planning and following a journey	D	Cannot follow any journey etc	This can lead to complete social isolation and significantly delay recovery. Must score at least 12.

Draft Assessment Thresholds

We have recently had sight of your proposed Assessment Thresholds, published in January 2012. Our Benefits Working Group has now had time to look at these, and we wish to make the following comments.

The proposed thresholds are quite clear, but we still doubt that many people with mental health problems will qualify for more than the standard allowances. This is particularly true of the Mobility Component, where we feel that not enough emphasis is placed on the psychological effects of travel and transport, and the consequences for people who need to attend therapy or treatment some distance from their homes. The effects of social isolation are also not fully taken into account.

Also, you have included only two examples of mental health problems in your Case Studies. Both of these are around Depression which, although an important and debilitating condition, is by no means the only serious or disabling example. We feel very strongly that if these case studies are intended as a guide for future assessors, there must be at least two more examples; we suggest Bi-polar Disorder and Schizophrenia. Both of these are long-term and fluctuating conditions which seriously affect sufferers in terms of employment, social exclusion, medication, therapy and other treatments, and general ability to lead a "normal" life.

For many people with these conditions, the only possible outlet for their energies is volunteer work, where they are not required to work regular hours and cope with the pressures of paid employment. They can still make a contribution, but only when well enough to do so. If this group suffers financial penalty as a result of changes to DLA/PIP, there is a real risk that many will end up back in acute care, and the cost of this to the taxpayer will far outweigh any savings made in benefits payments.

We attach three suggested new Case Studies; one for Bi-polar Disorder, one for Schizophrenia, and one for Anxiety Disorder. We believe these will give a much more accurate picture to assessors of what they are likely to face, and how to respond. We at the Mental Health Action Group are somewhat dismayed that, once again, a major Government Department and its officials seem largely ignorant of the breadth and depth of mental health conditions, despite the fact that large, national mental health charities have been involved in the drafting of these proposals. We suggest that mental health awareness training be made a priority for your employees as a matter of urgency so that dreadful mistakes and omissions are not made in the future.

Case Study A

Angela is 48. She was diagnosed with Bi-polar Disorder ten years ago. There have been three subsequent admissions, but none in the last three years. Angela takes medication to manage her illness; when in the manic phase, she takes stabilisers, and when in the depressive phase, she takes anti-depressants. Her condition fluctuates unpredictably through cycles of varying length, depending on time of year, social interactions and crises, and physical health issues. When depressed, Angela can be very ill for many days, and unable to focus or become motivated at all, requiring a great deal of help from her partner/carer. When in the manic phase, she is prone to unrealistic or unfeasible plans and actions, including making financial commitments which she is unable to meet. This has meant that employers are reluctant to engage Angela, so she does occasional unpaid work for a voluntary organisation when well enough. She attends therapy sessions at her nearest centre (ten miles away) twice a week, plus a local day centre twice a week. However, when very ill, she cannot travel alone or be relied upon to complete the journey without supervision.

Likely Descriptor Choices

Activity	Descriptor		
1	D	Needs prompting to either prepare or cook a simple meal	2
2	D	Needs prompting to take nutrition	4
3	C	Needs supervision, prompting or assistance to manage therapy that takes up to 3.5 hours a week	2
4	A	Can bathe and groom unaided	0
5	A	Can manage toilet needs or incontinence unaided`	0
6	C	Needs Prompting to dress, undress or determine appropriate circumstances for remaining clothed	2
7	A	Can communicate unaided and access written information unaided or using spectacles or contact lenses	0
8	B	Needs prompting to engage socially	2
9	B	Needs prompting to make complex financial decisions.	2
10	B	Needs supervision to follow a journey to a familiar destination	15
11	A	Can move at least 200 metres unaided	0

Total Points

Daily living activities = 14. Enhanced rate Daily Living component.
Mobility activities = 15. Enhanced rate mobility component.

Explanation

Angela can travel when well, but always needs help and supervision.

Case Study B

Bill is 27. He was diagnosed with schizophrenia at age 17 whilst still at college, and had to drop out of his A-level studies. He has been admitted to acute psychiatric care on many occasions, often requiring an extended stay for intensive treatment. He is currently undergoing long-term psychodynamic psychotherapy at a centre some miles away, three days per week.
Bill often suffers from delusions and psychosis, and has to be prompted to maintain his medication regime. He has attempted suicide twice, and self-harms on a regular basis. Bill has to be taken for his therapy sessions by a carer as he suffers panic attacks when using public transport. He is in sheltered housing and has floating support from social workers and support staff who ensure that he takes nutrition and is able to get up in the mornings and dress and groom himself. Bill's support needs are likely to remain intensive and long-term as his communication skills are now limited and he seems unable to convey when he is unwell.

Activity	Descriptor		
1	D	Needs prompting to either prepare or cook a simple meal	2
2	D	Needs prompting to take nutrition	4
3	E	Needs supervision, prompting or assistance to manage therapy that takes between 7 and 14 hours a week	6
4	C	Needs prompting to groom	1
5	A	Can manage toilet needs or incontinence unaided	0
6	C	Needs prompting to dress, undress or determine appropriate circumstances for remaining clothed etc	2
7	A	Can read written information unaided	0
8	D	Cannot engage socially due to such engagement causing either: 1. Overwhelming psychological distress to the individual, or 2. The individual to exhibit uncontrollable episodes of behaviour which would result in a substantial risk of harm to the individual or another person.	8
9	D	Cannot make any financial decisions at all.	6
10	D	Cannot follow any journey because it would cause overwhelming psychological distress to the individual	10
11	A	Can move at least 200 metres unaided	0

Total Points

Daily living activities = 29. (Enhanced rate daily living component)
Mobility activities =- 10. (Standard rate mobility allowance.)

Explanation

Bill is clearly very ill over the long term, and requires intensive help to lead his daily life and maintain his general health and wellbeing. He also requires some support to travel to and attend his therapy sessions.

Case Study C

Kerrie is 37. She has been a mature student at a university some 130 miles away, but has had to give up her studies due to increasing illness. She has been diagnosed with severe Anxiety Disorder, and is now so ill that she cannot leave her flat in a small village. Even going to the local shop is now an impossible effort, and she is effectively reliant on social services to get her shopping. She is receiving medication to help with the panic attacks, but this makes her lethargic and unable to co-ordinate her movements, and often causes shaking and tremors. Kerrie has no contact with people other than carers. She has been placed on an intense psychotherapy programme, but is unable to travel to the therapist. Even planning such a journey leaves her with overwhelming mental distress which can last for many hours or days. She sometimes feels so depressed that she does not eat or shower regularly, despite help from her carers. She often does not change her clothes, and cannot manage simple financial decisions. It is likely Kerrie will have to be re-admitted to an inpatient mental health ward at the local NHS Trust fairly soon.

Activity	Descriptor		
1	D	Needs prompting to either prepare or cook a meal	4
2	D	Needs prompting to take nutrition	4
3	F	Needs supervision, prompting or assistance to manage therapy that takes at least 14 hours per week.	8
4	E	Needs supervision or prompting to bathe	2
5	A	Can manage toilet needs or incontinence unaided	0
6	C	Needs prompting to dress	2
7	A	Can communicate unaided	0
8	D	Cannot engage socially due to such engagement causing overwhelming psychological distress	8
9	D	Cannot manage financial decisions	6
10	D	Cannot follow any journey because it would cause overwhelming psychological distress	10
11	A	Can move at least 200 metres unaided	0

Total Points

Daily Living Activities = 44 points (enhanced rate daily living component.)
Mobility activities = 10 (standard rate mobility allowance.)

Explanation

Kerrie is clearly a very ill person with severe problems coping with everyday life. Her needs are not currently being met by the NHS or social services, and she may need a stay in hospital to stabilise her condition. It is hard to see how she will be able to improve in the short term.

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Overall Findings

We believe that there has been some minor improvement in appreciation of the barriers and problems faced by people with severe and enduring mental health issues. However, we remain unconvinced that people will be able to score sufficient points during the assessment process to enable them to qualify for PIP, especially the enhanced allowance.

There is a clear difference between physical and mental disability, but some people can have both, and this needs to be fully reflected during assessment.

The Mental Health Action Group is led by people who have received or are receiving mental health services, and therefore has a vast range of experience and knowledge that goes beyond even diagnosis and treatment. Our experience shows that many people can manage reasonably well on their current financial support through DLA (and sometimes ESA). They are already under severe pressure financially due to rising living costs and static payments; the added stress and anxiety being caused by uncertainty about DLA is already having an effect well in advance of any changes actually taking place.

The Mental Health Action Group appreciates that savings in the benefits budget have to be achieved. However, the risk is that very ill people will be made even more unwell, or their recovery programmes adversely affected by badly-conceived changes through the introduction of PIP. People with mental health problems are already discriminated against with regard to employment, and this situation has worsened in the current economic climate, which means that their prospects of finding work are near enough nil. Not only that, but one vital avenue for employment of disabled people, namely Remploy, is closing more than half its sites across the UK, reducing even further the opportunities for work.

Conclusion

It is not enough to give people the barest minimum on which to "survive". This means a constant struggle to feed, house and manage themselves, without any realistic hope of being able to get a job or improve their situation. You must think very hard about this before implementing PIP. The consequences for individuals may be very serious indeed, and the consequences for the NHS could be extremely costly.

There is another aspect to all of this. We must look at PIP and its likely effects in a holistic way. Support for people with severe and enduring mental health problems is under threat from a variety of sources; the NHS and Mental Health Trusts are cutting or scrapping recovery programmes; Councils are reducing or cutting support services (such as day centres and social support); and the voluntary sector (which plays a massive role in mental health issues) is losing funding streams which previously helped support sufferers.

Speaking to our members and associates, it is already clear that many of them believe that they are under attack from many quarters, and this is having a serious effect on their ability to cope, recover and have any hope of a reasonable life. The change from DLA to PIP is seen as yet another such attack.

Can we make a final plea; whatever the outcome of this consultation, can you produce any future documentation in Plain English please? I know that the DWP has made strong efforts recently to improve its communication with the general public, and this is to be applauded. The use of straightforward language and the reduction in jargon will be a massive benefit to those people whose illness, cognitive skills and concentration levels can vary widely.

Many thanks

Yours truly

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