

Great Expectations: the truth about PIP

Presentation to the NADP Conference, London, April 2013 Mark Baker.

Thank you very much for the invitation to come and speak this morning. Just to give you a little more background about myself, I worked at RNID (now Action on Hearing Loss) between 2004 and 2012. I was also



the policy chair for the Disability Benefits Consortium, a coalition of more than 50 national organisations that represent the needs of people who rely on disability benefits.

I have to admit that the current series of changes to the social security system can be difficult to

grasp, and I'm supposed to be an expert! What with Employment and Support Allowance, the benefits cap, the Bedroom Tax, Housing Benefit reform, the abolition of the Social Fund and the looming spectre of Universal Credit, its no wonder that people are confused.

Hopefully, I will be able to shine a little light in the gloom. However, I must make it clear that I will not be able to say with any certainty whether any individual is likely to be able to claim Personal Independence Payment (PIP). The benefit is, after all, barely a fortnight old. As we already know from Employment and Support Allowance, there's a vast sea of uncertainty between the stated intentions of a benefit and its practical implementation. Therefore my comments are

an interpretation.

Can I just start by asking how many people currently get DLA? I see there are quite a few, thank you. I assume that most people will be getting either middle or lower rate care and possibly lower rate mobility.

Those are the usual combinations we found, and I know that particularly from working with sign language users, and having run RNID's welfare rights service. Before I get to the nitty-gritty, I want to look at the history of Disabled Living Allowance (DLA), and the reasons given for change and perhaps cast a critical eye over those reasons. DLA was introduced in 1992 to replace Attendance Allowance for people of working age, adding in the mobility component. It was understood from the start, however, that DLA was designed to help people meet the extra cost of disability generally, but not meant to meet the entirety of the extra costs.

Over the course of the last twenty years the number of people receiving DLA has grown considerably. Some of this is due to the fact there have been changes in case law that have recognised the extra costs faced by different groups of people. For instance, it was only a few years ago that deaf and deafened people were found to be eligible for the mobility component of DLA, on the basis of needing help to negotiate unfamiliar environments. And only late in 2011 were blind people guaranteed access to the higher rate of mobility. It cannot be doubted that during its relatively short lifetime DLA has helped hundreds of thousands of people to live independently and enabled them to take more control over their own lives. In many ways DLA was the original personal budget, allowing people to choose the support they wanted when they wanted it.

When it was first announced that the government wanted to look at DLA, alarm bells started ringing across the disability sector. After all, it was unlikely that any review would be set up with the intention of increasing the budget. The first proposal was to remove the mobility component from people in residential care, something on which successful lobbying on behalf of the disability sector forced a U-turn in 2011 with the government recognising this would restrict independence and be counter-productive to people's well-being. However, the fact that such a problematic policy was allowed to get so close to the statute books was worrying. These concerns were borne out in full when initial meetings were held with civil servants from the Department of Work and Pensions. It was made clear that the sole driver for reform was financial. The department was working to a target that meant there would be a 20% reduction on projected spend on the benefit within three years, amounting to some £2.2 billion. Any new benefit would be designed to deliver these savings rather than seek to decide who needs support and how much. This would not be an objective benefit but a benefit with an objective. Various figures abound for the estimate of how many disabled people will lose their benefit, but it is generally agreed that the eventual number will be around 600,000.

One of the key points is that the government chose not to reform DLA, but to replace it with an entirely new benefit Personal Independence Payment (PIP). It hasn't been widely noted what the ramifications of this will be. By replacing DLA the government wipes out twenty years of case law and with it the advances that have been made in recognising the wide range of extra costs that people face in the course of their everyday lives.

Basically, it wipes the slate clean. One of the government's key arguments has been the spiralling cost of the benefit though it has to be said that one of the main reasons for this is that people who start to claim for DLA before their 65th birthday remain eligible for it after their 65th birthday. The fact is that people are living longer and healthier lives. The average length of a DLA claim is much longer than in 1992 or even in 2002. Ironically, it could be argued that DLA has played a part in allowing people to live longer and healthier lives. There has always been much talk about fraud, people playing the system. Quite simply DLA has very little fraud, 0.5% of the budget, and indeed the majority of this is actually official error, not fraudulent claims. It is one of the most efficiently-run benefits in the UK.

Another argument is that DLA is often rewarded for life, and people are not reassessed regularly - there may be some merit in this position. But it has to be recognised that the vast majority of claimants will have long-term or permanent disabilities that will not improve. People are not going to suddenly regain their hearing or their eyesight. If there's a place for more frequent reassessment, then it would be to discover whether a person's condition has deteriorated, as is more likely to be the case. I fear that calling people in to be assessed more often will simply prove to be a waste of public money, money that could be better spent in supporting those people. A final justification for reform has been the contentious claim that DLA can act as a barrier to work, as it provides people with a financial cushion. I suspect very few people will be willing to survive on the amount of money they get from DLA. Indeed some research I conducted last year shows that DLA helps people to get to work, and to stay in work, often

allowing them to afford support and help such as a Smartphone or transport with a Motability Scheme, independent transport where public transport is inadequate or inaccessible. I met a number of people who told me if they lost DLA they would have to give up work. In short then I return to the point that reform is solely about saving money, which means that hundreds of thousands of people are going to lose out, not merely financially, but in terms of independence and quality of life.

Having detailed the thinking, or lack of it, behind the reform, I now turn to nuts-and-bolts. In many respects, PIP is very similar to DLA. In order to qualify you have to be aged between 16-64. People 65 or over will continue to be eligible for Attendance Allowance which is not being reformed. Those under 16 will continue to be eligible for DLA until they reach their 16th birthday when they will have to make a claim for PIP. You will need to have a condition that is expected to last for 12 months. If starting a new claim, you will have to be eligible for the benefit for three months before you are paid. There will be no backdating of this payment to compensate for this period. This qualifying period will not apply to people who are currently receiving DLA. Originally the government wanted to put in a six month qualifying period but luckily lobbying had that reduced to three.

Current DLA claimants will be asked to make a claim for PIP from October 2014 unless you have a fixed term award that expires before the end of February 2014 in which case it will be October of this year. When you receive what the DWP is calling an invitation to claim, you have 28 days to make it - that is all. details on how to do this will be available on the DWP website or from other advice centres that I really can't go into here or I

would be all day! PIP is currently being piloted in the north-east and north-west of England with national roll-out scheduled for June 10th this year. After this date, no new claims for DLA can be made. Like DLA, PIP has two components, Daily Living and Mobility. Unlike DLA, PIP will only have two rates of payment for the components. And these will be referred to as standard and enhanced rates. The standard rate for daily living is £53 per week, and the enhanced rate £79.15. For mobility, the standard rate is £21 per week and the enhanced rate is £55.25.

In order to qualify you will need to score a certain number of points in face-to-face assessment. You will need eight points to receive the standard rate and twelve points for the enhanced rate. I will come on to the points in a moment. Depending on where you live, the assessment will be carried out either by Capita or ATOS contracted health care professionals. Lucky you if you live in a Capita area! Because they seem to be taking issues of disability much more seriously in their planning - they for instance will be conducting a majority of interviews in the individual's home. They in fact have two disabled people at the very top of the organisation.

ATOS have a very different attitude. You will be allowed to take someone with you to the assessment. As I will point out later, I think that's a very good idea. The final decision on whether to award PIP is in the hands of the Department of Work and Pensions with an award either being short-term, up to two years, or longer, which could be five to ten years, depending on the perceived likelihood of a change in condition or impairment. There will be a very, very small number of permanent awards, though all claimants will be contacted periodically to see

if their conditions have altered.

The most relevant activity for deafened people is called communicating verbally. Points are awarded as follows (remember you need eight to get the standard rate and twelve to get the enhanced rate), and I'm just quoting directly from the Welfare Reform Act. If you can express and understand verbal information unaided you will score zero points. If you need to use an aid or an appliance to be able to speak or hear you will score two points. If you need communication support to be able to express or understand complex verbal information, you will score four points. If you need communication support to be able to express or understand basic verbal information, you will score eight points. If you cannot express or understand verbal information at all, even with communication support, you will score twelve points. It's worth looking at these in more detail because they allow a degree of interpretation. While it can be difficult to predict how these criteria will be applied in an actual assessment, we can perhaps start to draw some preliminary conclusions.

The first thing to note is that, as with DLA, all assessments will be undertaken on the basis that any aids or appliances that a person usually uses are in use. This means that someone who habitually and successfully uses a hearing aid or a cochlear implant would be likely to score only two points, well short of the amount needed to qualify. There is debate also to be had about the difference between complex and basic verbal information and the nature of communication support. I remember sitting round the table in the Department of Work and Pensions having various convoluted arguments as to what basic or complex means. Basic information according to the guidance

published by the Department refers to information in your native language, which in this case would be English for BSL users, conveyed verbally in a simple sentence. Complex information refers to information in your native language conveyed verbally in either more than one sentence or in one complicated sentence. I'm unsure still as to how this is going to be interpreted in a face-to-face assessment, and I think the biggest worry here is having consistency of decisions between different assessors who may see the difference between complex and basic very differently.

Communication support is defined as being "support from a person trained or experienced in communicating with people with specific communication needs including interpreting verbal information into a non-verbal form, and vice versa". Basically that is their description of sign language but also for people with cognitive learning disabilities as well. Though the criteria appear to have been designed to recognise the needs of deaf sign language users, but take no explicit account of people who do not sign, as it stands even the most basic sign language users will score only eight points, and qualify for the standard rather than the enhanced rate of care. In order to qualify for the enhanced rate, somebody will probably also have to have some form of cognitive or physical disability that would impair their ability to sign. As regards deafened people, particularly those who rely on lip-reading or STTR, the situation remains unclear. My initial suspicion is that they will be seen as being able to express and understand basic information, therefore scoring only four points.

This may not necessarily be the case. Again I have to underline that this is my interpretation. However, one key concession that appeared very late in the day during

the Welfare Reform Act's passage through Parliament was the introduction of guidance which is now written on the face of the Bill that a person must be able to carry out their activity safely, to an acceptable standard, repeatedly, and in a reasonable time period. This is where there may be leeway in that while someone may be able to comprehend basic verbal information in small doses they may not be able to do so to an acceptable standard, or repeatedly, or within a reasonable time period. It might take people longer to do so, they may be confused and they may not be able to understand at the first attempt. However, this may also be construed as being evidence only of not being able to comprehend complex information. I will come back to this in a second.

I want to turn to the mobility component that some people here may receive. Under the criterion for planning and following journeys, while it does state that you can score ten points for not being able to follow the route of an unfamiliar journey without another person, assistance dog or orientation aid, the note states specifically that this does not include speech. Basically, deaf and deafened people will not be eligible for the mobility component of PIP unless they have other qualifying conditions or disabilities. So far so bad.

So at the moment it seems that sign language users will qualify only for the standard daily living rate, and that lip- readers will possibly not qualify at all. But as we know, lip-reading is not an exact science. Many people prefer to have an intermediary with them to help with communication. To this end, my advice to anyone attending an assessment would be to demand that a lip-speaker or STTR be made available for the face-to-face interview. Not only would this provide some evidence of

the need of the individual for that support, but also it would bring home to the assessor the sheer difficulty of providing one. Failing this, it's vital that the individual does not attend alone, as doing so may be seen as evidence that he or she can communicate effectively without assistance. It goes without saying that this runs contrary to everything we believe about inclusion and promoting independence, but I firmly believe that people wanting to claim PIP successfully will have to make themselves look more dependent on others than they really are. The onus will be upon the individual to prove that they cannot function without support.

Finally, then, a few other considerations. There has been some concern expressed about the possibility that people may be assessed on the basis of their being able to use an aid or adaptation that they do not currently have access to. Some more alarmist people have suggested that deaf people may be forced to consider a cochlear implant. I can lay that myth to rest. No- one will be required to undergo invasive surgery. However, it may be suggested that people should use hearing aids more, if they do not use them currently. It's important, therefore, for individuals to be clear about why this would be unsuitable - for instance, people with tinnitus who can't use hearing aids for long periods of time.

It is unlikely that assessors and decision makers will know much about the benefits and the limitations of hearing aids. I also feel it's worth mentioning a little bit about Universal Credit, but I don't want to get into it too much. Again, I will be here for the rest of the day, and you will all want to leave. But this is the flagship of welfare reform for the government, and will signal a dramatic change in the way benefits are paid.

DLA and PIP will not be affected by this, and remain outside of the Universal Credit envelope. However, for those people that have other benefits, Universal Credit will create some changes, with monthly payments rather than fortnightly payments, and increased conditionality. And there is a danger with the shift to monthly payments that people who currently have very low incomes and therefore budget on a fortnightly, weekly or even daily basis, will find that budgeting on a monthly basis will prove to be quite difficult and challenging for them. Also, I was quite shocked to discover yesterday that Universal Credit pilots are only going to be piloted on those people whose claims will be the easiest to process. That means all the difficulties, all the problems, all the complexities of Universal Credit, of which there are many, won't actually be tested in the pilots, which rather defeats the object of a pilot. It's reckoned that only 300 people will go through the Universal Credit pilot before it's rolled out, which is shocking.

Finally, I can reassure people that most of the passporting that occurs with DLA will continue with PIP. However, the large numbers of people who will lose out with reforms will mean that they will no longer be able to claim extra benefits, including carers allowance or access to Motability.

I know that this has been rather a whirlwind tour of some pretty major changes, and much of what is to come will depend upon interpretation and refinement, and I suspect that we will see a number of appeals against decisions and a resultant expansion of case law, as eligibility is debated and decided upon. Now, of course, changes to the appeal process, to legal aid, and the closure of many advice centres, may mean that there will be many fewer appeals than with Employment

Support Allowance, and that change will be slow, but even the most carefully designed legislation has the tendency to evolve and expand over time.

Questions to the speaker.

Can I ask that you, first of all, give your name, and then ask the question. And in order the hands went up is Mike Theobald, Michael Somwaru, Mark West, Lidia Best and Anthony Jefferson, and then Alan Roberts. So can we start with Mike Theobald.

Mike Theobald. Mark Baker suggested taking somebody to the assessment with you. When I was assessed for DLA I was unfortunate to have a blind person on the panel, who did not see what was happening and that I had communication support with me, and just heard my voice and said, "How can you possibly be deaf?" and that affected everything. It took two-and-a-half years with a Commissioner and appeals to get that reversed to what it should have been. If your voice is clear, a blind person will not accept you as being deaf, so be very careful who is on the panel. If they don't understand deafness they don't understand that if you miss just one word of a sentence the whole sentence is meaningless. So be prepared, if you do go.

Mark Baker. That's very good advice indeed. And again, I would come back to face-to-face assessments. Capita, who are doing about half of the assessments under PIP, are promising, where possible, to have someone with knowledge of a person's condition or impairment undertake the assessment. Unsurprisingly, ATOS have made no such claim themselves, so I do think there's going to be some significant difference between the two companies' approaches. But very good

advice.

Michael Somwaru. When PIP starts what happens if one has to appeal? Is it the same method as DLA with three people on the bench? If you lose an appeal how long will you have to wait to apply again?

Mark Baker. The appeal procedure will be very similar, but one of the things that's been worked out between the Department of Work and Pensions and the Department of Justice - and partly, I think this is because Chris Grayling moved from one to the other - is that when you make an appeal against a decision, the first port of call will be reconsideration by the Department. This can take three to six months, at best. This is intended to reduce the burden on the appeals system, which is currently swamped by Employment and Support Allowance. It has to be said that more recently with DLA the reconsideration process was improving. It was far from perfect, and it was slow. The fear is that people will be put off if they have to wait another three to six months before they can make a proper appeal. My advice is to take what legal advice you can, go for the reconsideration process - you have no choice - but during that period you can, of course, be preparing for an appeal, so that when the decision of the reconsideration comes through, you have everything ready to put it in on that very day. So it's about being prepared. As for the timescale I am not going to speculate. As we know, Employment and Support Allowance has a massive backlog, where we are having people who are being called in for assessment within days of having their appeal decision. My guess is that it's going to be some considerable time. It's not going to get better.

Mark West. I work in the Citizens Advice Bureau on south-west London, and we deal with quite a lot of DLA, and we have the wonderful experience of dealing with ATOS. At the moment, with DLA, we expect that, whatever is said at the beginning, ATOS will say no, and so we gear up to help our client appeal straightaway. So we put in an appeal straightaway. It then goes for reconsideration, and at the moment, most of the time, the Department decide to stick with their original decisions. It then goes on to the tribunal, and in more than half the cases, we win. Now, I am interested as to what Mark thinks will change in relation to PIP. It seems to me that the same process should go ahead - that's to say that you appeal straightaway, as soon as you get the decision that you are not getting your PIP - and so then, whatever happens about the reconsideration, you are on the right path. And the other thing is that we will support the client, and the key thing about that is not just that somebody goes to the appeal with the client, but that we put in a reasoned submission to the tribunal, that goes through and maps out all the points. And I would just like to say that in relation to somebody being deafened, it is often the case that there are other disabilities and other problems, so that, when you are trying to stack up your points, you may not be trying to stack them up just on your deafness. And we make every chance to increase the areas in which we are putting forward the submission for points. That's what we do at the moment, and I think we will do that for PIP as well. The other question I would like to ask Mark is that he said that the slate is wiped clean, but surely, if there's still a tribunal process, they won't completely ignore all the decisions that have been taken in the past. They may have to be adjusted in relation to the new legislation, but surely they won't all just be ignored and

thrown away.

Mark Baker. Yes, I would agree entirely with what you say in terms of gearing up early for appeal. And in fact I think under PIP, given the points, it's actually going to be more important for people to stack up as many points in as many areas as possible, because it's just going to be that bit harder to cross the line. With regard to case law, the regulations are sufficiently different, and the criteria are sufficiently different, for a tribunal not to have to consider what's happened under DLA. I really do think this is the sole reason why DLA is being replaced and not reformed. Yes, some tribunals may make decisions based upon what they know of DLA, but the structure of PIP, at the legislative level, is sufficiently different for decisions not to be transferable.

Lidia Best. I have gone through the whole Employment and Support Allowance process in relation to ATOS, supporting my husband. One of the most important things is that ATOS will not provide communication support, despite being asked to do it. And a lot of times people actually agree, as my husband did, to go along with the process, instead of actually saying, "No, you did not provide the support." This is one of the biggest problems. A lot of people don't know their rights, that they can refuse to attend the actual assessment if there is no communication support, despite writing it down on the form. My husband lost his assessment, but I actually put in the appeal, which was refused, going straightaway to the tribunal. The judge reversed everything completely, and accepted what I asked for, to put my husband in the work support group, something which all deaf people really need, and that was important. I think it is important to raise this awareness. As you said yourself, you have to come with

communication support. If it's not provided, and ATOS is famous for this unfortunately, then walk away and say, "I need a new appointment with communication support." Would you agree?

Mark Baker. Absolutely. Without getting technical here, in terms of the Disability Discrimination Act, as amended, when carrying out an assessment, an assessor is acting - legal speak now - "in the capacity of a public authority". That means they are bound, by law, to consider the needs of disabled people. If they fail to provide communication support when asked, they are breaking the law. It's as simple as that. And you can, as Lidia says, refuse to attend, on the basis that your needs are not being considered or met. So, yes, very good advice again.

Mary Wilkinson. What happens if you refuse to attend then?

Mark Baker. It's a difficult one to answer actually, because so few people do refuse to attend, because they feel that there's pressure to do so. What you say is, "I am sorry, I can't do that. Give me another appointment, with the support." Therefore, you are not refusing to attend - you are asking for it to be rearranged. I think that's the way you have to look at it.

Anthony Jefferson. I read recently on social media that the Minister for Disabled People is very ignorant about the problems and made the most appalling public statement. How can a Minister in government be so ignorant about our everyday problems? Secondly, is Universal Credit and PIP means tested? Mark mentioned about DDA has been replaced by the Equality Act. The information is not going out at all. We are not raising the

standards of the Equality Act. Finally, Mark mentioned cutbacks in legal aid and Citizens Advice being under pressure, but many years ago I had some help from the university law centres, they give their services for free. So please do use their offices, if you can.

Mark Baker. I am not privy to the workings of the Minister for Disabled People's mind! People were quite pleased to see Maria Miller go earlier this year, but Esther McVey seems to be cast in very much the same stone. The Ministers that we have had for disabled people, over a period of time, have not had any background experience or interest in disability issues or disabled people. It's often seen as a minor ministerial role on a promotion path that people are just given to see if they can cope with it. Very few politicians I have met have been interested in making anything of a career out of being interested in disability. I would say Ann McGuire, the current Shadow and a former disability minister, has shown a long-term commitment to that. I have met her on many occasions, but she is the exception, rather than the rule. PIP is not means tested. Universal Credit is all about flexible means testing. I won't go into it now but the amount of Universal Credit you receive can change on a monthly basis depending upon income. It also relies upon a very complicated computer system that isn't working properly. They have had four IT heads of Universal Credit in six months, and they've got another one starting next month. It's chaos. That's why I don't want to talk about it! When I talked about the DDA, I meant the DDA as amended by the Equality Act. The one good thing about the Equality Act is it does impose this public sector duty that means that ATOS or Capita, or whoever, must consider the needs of disabled people. So that's the element of that. Yes, very

good advice. Law centres or anyone that can provide free advice is very welcome. And I think, again, without getting into too legal, technical issues, it may be a thing that organisations take class actions against types of decisions, rather than individual decisions. This may be the way to move the benefit forward.

Unknown speaker. What does that mean, class action?

Mark Baker. It means groups of people working together.