

Outline proposal from the Haemophilia Society for reform of infected blood support payments and their interaction with means tested benefits

The proposal

This is a proposal to simplify the current infected blood scheme payments by, increasing them and making them analogous to an occupational pension and so therefore lift almost all recipients above means tested benefits level. We respectfully ask that the Infected Blood Inquiry as well as the UK and devolved governments consider this as an option.

Currently, it appears that, the vast majority of people infected by NHS blood and blood products receive both scheme payments and also means tested benefits (MTB). This may be at least 80% if not 90% of those receiving scheme payments. Most are single people. A minority appear to be tenants and therefore receiving help with rental costs from Housing Benefit or Universal Credit. Most will also be receiving Council Tax Support from their local authority. The majority receive Income Related ESA and almost all of these qualify for both the Support Component the Enhanced Disability Premium and the Severe Disability Premium in the calculation of that benefit.

The problem

MTBs inevitably involve

- Intrusive questions about personal and financial circumstances, therefore increasing stigma and distress for a group already harmed by their experiences.
- Inhibition of the ability to lead a "normal" life because of the need to notify changes of circumstances such as starting paid work, receiving income or capital, making difficult decisions about moving in with a partner.
- A poverty trap created by the taper and cliff edge effect of rules on paid work and income. A disincentive to improving one's financial circumstances.
- Complexity and a tendency to make errors by both DWP staff and claimants alike.

For the infected blood community there are additional issues

- The fear of being subjected to a DWP fraud or compliance intervention about scheme payments and/or lump sums paid in the past.
- Having to explain their sensitive medical history to DWP staff.
- The stigma and risk of breach of confidentiality of explaining to creditors, landlords and others what their support payments are for.

High level reform proposals

- Increase existing scheme payments by average amount of MTBs with annual updating. A typical MTB is £200 pw for a single person plus Council Tax Support.
- Address various inconsistencies in payments and between the four national schemes where development by accretion has led to an appearance of unfairness, especially as the infections arose before devolution in Wales and Scotland.
- Make the enhanced payments tax-free but also change them so they count as income for means tested benefits in the same way an occupational pension is.

- Administer payments via an existing NHS payment scheme as a special NHS pension scheme; they already administer NHS pensions.

The effect of these reforms

- They would lift recipients income above MTB levels and therefore off MTBs except for a small minority with high rents and/or dependant children.
- Remove stigma, intrusion and other effects of means tested benefits on individuals.
- End wasteful and distressing fraud and compliance interventions by DWP because people no longer receive MTBs.
- Reduce administrative cost for DWP by this simplification measure which also lessens their need to means test a group with unusual financial circumstances.
- The net cost is significantly less for government than the gross cost of increasing scheme payments because of the reduced expenditure on MTBs.
- To reduce stigma by the payments being badged as a special payment or pension scheme.

Some issues

- Most infected people will have sufficient National Insurance payments or credits to qualify for the maximum flat rate state pension in the future. Some may need to continue their ESA claim on a “credits only” basis to build up sufficient to qualify for a maximum pension. Individual advice from DWP and/or HMRC will be required to identify those who should maintain their ESA claim to get National Insurance credits.
- Close, ongoing work will be needed by DWP and scheme administrators to quantify numbers of people and amount of average MTBs. This may require data matching and/or survey work and possibly informed consent from individuals as well as modelling this proposal.
- Consider whether one UK-wide payments scheme should be established. Savings on DWP benefits won't accrue to devolved schemes and one UK scheme avoids this problem as well as recognition of infections occurring pre-devolution.
- A process to notify DWP of individual changes of circumstances at the date of change will be required
- Consultation and engagement with the infected blood community is essential.
- The reformed payments scheme can operate in parallel to any compensation lump sums which may be paid.

Plan B

If the above cannot proceed and if payment schemes continue:

- DWP and schemes must issue clear written, individualised advice to recipients about the effect of payments on MTBs (they are disregarded), what they are required to tell DWP and how to do so.
- A process is needed for managing notifications of support and compensation payments, at least on a short term basis, to a nominated DWP team.
- DWP to upgrade their computerised customer database to record income and capital to be disregarded. This will affected a wider range of MTB claimants.
- These measures should greatly reduce wasteful and nugatory fraud and compliance interventions and reduce anxiety felt by many that they can be subjected to these at any time.
- If lump sum compensation is to be paid, it is assumed that these will be disregarded for MTBs (rather than having to be held in a trust as is usually the case with personal injury damages). Therefore it is

essential that clear written information is provided about issues which include the £85,000 limit on savings per financial institution under the Financial Services Compensation Scheme, the need to keep lump sums separate from other capital, the option to seek regulated Independent Financial Advice and how to find it.

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