Jan Barlow

From:	Patrick Spellman <flourpowerpat@GRO-C>
Sent:	04 March 2015 14:20
To:	Roger Evans
Cc:	Jan Barlow
Subject:	Friday Board Meeting
Attachments:	hansard.docx

Roger
I've trawled through the Official Report of th Commons' debate after the APPG Report was published. Attached are extracts relevant to the MFT, particularly Burt MP's observations in the House about this unfit trust

In the APPG Report , the first para on page 81 states that APPG has also been approached, in confidence, by MFT TRustees who have stated they are not happy with how the charity is presently run, and have expressed particular concern about the links between MFT and DH.

Some of this may be useful for discussion on Friday.

Pat

House of Commons

Thursday 15 January 2015

Column 1025

Backbench Business 11.29 am

Contaminated Blood

Nadhim Zahawi (Stratford-on-Avon) (Con): On the point about the support mechanism, does my right hon. Friend agree that it is unacceptable that the very organisations that were set up to support individuals, such as the MacFarlane Trust, do not treat beneficiaries equitably? My constituent who went to the trust and questioned the response times was branded a troublemaker

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and her applications for grants were either delayed or, in some cases, frustrated completely. That is the reality on the ground. Will he say something about some of those organisations?

Alistair Burt: My hon. Friend is right that many beneficiaries have expressed deep concern about the workings of the trust. The all-party group report that came out yesterday will be addressed by other colleagues. On the MacFarlane Trust in particular he should know that I share his concerns. I do not believe that that trust is salvageable or saveable, and I will speak about that later.

....

As I said to my hon. Friend the Member for Stratford-on-Avon, I am not sure that I fully share the conclusions of the all-party group's report with regard to the

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MacFarlane Trust. There is a great deal of detail in the report. As I was not responsible for compiling it, I can be lavish in my praise of the effort that went into it. A lot of hard work was done by a lot of people connected with the offices of the hon. Member for Kingston upon Hull North and my hon. Friend the Member for Colne Valley, and I am grateful for that. On the basis of information contained in the report and other information that we have, I do not believe that the MacFarlane Trust is saveable or capable of reform. I and others have seen a copy of a letter to the Secretary of State from two former trustees that is quite damning of its leadership, and one from some 68 beneficiaries that is equally uncompromising.

It would be unfair to go into more detail now. It may be that the trust has an impossible role. However, there should be no doubt that a body set up to support beneficiaries and those who have been victims of what happened is anything other than on their side—not an arm of Government, nor seen to be, and prepared to take on the Government to argue for the funds it needs without fearing a conflict of interest. The Department of Health has contributed to the situation by structuring too cosy a relationship, possibly in its own interests, and that has to stop.

Caroline Dinenage (Gosport) (Con): My right hon. Friend has worked very hard on this issue, as has the all-party group on haemophilia and contaminated blood. I attended a public meeting yesterday with survivors and their families, and there was a very strong feeling that they have just had enough. They have been through a series of betrayals and disappointments at the hands of those who were supposed to help them, including trusts, departments and the Government. Does my right hon. Friend agree that this is our last chance to get this right for those people who have to suffer so very much?

Alistair Burt: I thank my hon. Friend for her kind words, and I agree with her. I will come to the trust invested in us in a moment, but, given the effort that has been put in, the work being done by Members on both Front Benches and the acknowledgement that we all share this responsibility, perhaps there is a chance that we will get to where we want to be.

11.58 am

Diana Johnson (Kingston upon Hull North) (Lab):......................

In addition, I thank YouGov and the hon. Member for Stratford-on-Avon (Nadhim Zahawi), who generously helped put together the survey; the Haemophilia Society, which provides the all-party group's secretariat, and particularly its chief executive, Liz Carroll, without whose help we could not have conducted the inquiry or produced and printed the report; and Fiona McAndrew

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and Thomas Stephens, who both worked so hard to put the report together. I am also pleased that my right hon. Friend the Member for Leigh (Andy Burnham) is on the Labour Front Bench, and that the Secretary of State for Health and his Minister, who has direct responsibility for this area, are also present.

....

Just today I received a message from someone who said that the money they get from one of the trusts is now being spent on paying the bedroom tax—I am sure the Minister does not think that that is what trust money should be used for.

....

I will end with a quote from a person I think was very brave to come forward. She is an HIV infectee and the widow of an HIV-infected husband:

"I refuse to be a victim. Despite everything I cherish my life and count my blessings. I have faith that this will end soon and maybe then, my talents, intelligence, spirit, sense of justice, experience and energies can be better directed at contributing towards and being part of a better society. I pray for the day when this Trust is out of my life. I do not think that is much to ask."

Jason McCartney (Colne Valley) (Con):.........

As the Penrose inquiry is imminent and discussions on a final settlement are under way, the all-party group on haemophilia and contaminated blood, which I co-chair with the hon. Member for Kingston upon Hull North (Diana Johnson), set up a survey with the infected community to ask how it felt about current financial arrangements organised through the Skipton Fund, the MacFarlane and Eileen trusts, and the Caxton Foundation. The survey received 961 responses, the majority of which were unhappy with current arrangements. I thank Tom Stephens, and my hon. Friend the Member for Stratford-on-Avon (Nadhim Zahawi) for his co-operation, and of course Liz Carroll and the Haemophilia Society for their help in compiling this important report.

....

Mr George Howarth (Knowsley) (Lab):

.... My constituent is now 76 years old, and is herself in ill health. She is looking for answers to a number of questions that are still arising, and she hopes to receive those answers in her lifetime and as soon as possible. The family sent me the following statement, which they asked me to read out: ....

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The family make two specific requests. First, they call for the current support groups to be disbanded and a new, comprehensive method of support to be introduced to replace the support schemes that are currently available, which they consider to be confusing and unfit for purpose. Secondly, they call for substantial, regular financial support that will meet the care needs of those affected.

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Jenny Willott: Does the hon. Gentleman agree that, because we are talking about quite a small number of people, fairly generous packages of compensation would be affordable? We are not looking at millions of people; we are looking at a small number of people who have suffered very seriously as a result of the NHS.

Sir Edward Leigh (Gainsborough) (Con): Yes, I want to deal with that point, and I am glad that the hon. Lady has made that intervention. I can quite understand where the Government are coming from, but both my hon. Friend the Member for Aldershot and I—and others who have spoken—cannot ever be accused of wanting to waste public money. We are very aware of the pressures on Government. Again I am grateful to my constituent for some of the figures that have been given to me. He says—and I hope the Minister will reply to this point—that:

"The figures quoted in the Written Ministerial Statement are completely incorrect. The Government have refuted suggestions that they based their calculations on a typographical error in the Archer Report and claim that the costings were based on an average of £750,000 per person. The CEO of the Irish Haemophilia Society has confirmed that the average figures paid out in Ireland was 'around €350,000' per person."

So the total figure we are talking about here is £1.5 billion. That is very similar to the compensation paid to the victims of Equitable Life. I have campaigned on Equitable Life, as we all have, and it is pretty awful for someone to lose their life savings and there was appalling suffering, but at the end of the day they have lost their savings; they have not lost their life. So if we are prepared to pay this sort of compensation to the victims of Equitable Life, why do we baulk at similar figures for those whose whole lives have been ruined, and ultimately many of them lost?

....

Mrs Anne Main (St Albans) (Con):..........

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..... The funds set up to deal with the issue are not dealing with it and, if anything, are trying to avoid dealing with it if they can and keep money back.

We do not wish to save the state money because, as the right hon. Member for Cardiff Central (Jenny Willott) said, we are speaking about a relatively small number of people. Let us get the matter sorted. Let us put in place a fair system.

....

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Mr Andy Slaughter (Hammersmith) (Lab)

....

Let me say one quick word about the existing arrangements. The report is good. It produces a lot of evidence for why the current schemes are not working, and we have heard individual criticisms of Macfarlane, Caxton and Skipton. Having read the report, my conclusion is that none of the trusts and funds is fit for purpose. If they are to continue while we await a final settlement, we must have root and branch reform and the funds must be resolved into one effective body. The politics is wrong. The funds purport to be independent bodies, but they appear to be too close to the Department of Health, meaning they have neither the benefits of independence nor the clout of accountability that should lie with the Department of Health. At the same time, they have become part of this degrading process where sufferers, who are largely reliant on benefits, are effectively begging for resources and often living in a state of penury.

Huw Irranca-Davies (Ogmore) (Lab):

Column 1065

....

The Macfarlane Trust had recently sent us a 'disbursement of reserves' form, requiring personal and in depth information to enable us to possibly have some money for home improvements. My wife and I felt it was an extremely unjust and unfair way of attempting to distribute funds amongst sufferers of HIV and their families. Not everyone would, or could qualify as they were in rental accommodation, or perhaps their home was not in need of improvements. It was causing a divide amongst the few that have survived this atrocity and we refused to complete it as any reserves we felt need to be distributed equally amongst those of us that are left. It seems the discrimination, separation and sheer lack of consideration for the primary beneficiaries is still very much in evidence."

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My constituents, like those mentioned in so many stories today, are asking not to have to go out with a begging bowl in complex situations, having to prove that they are worthy. This is an entitlement, not something to be begged for. They want some form of inquiry and a clear apology and there is a crying need for root and branch reform of the structures that have been put in place to help them. This is not working satisfactorily.

Andy Burnham (Leigh) (Lab):

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If the Minister, working with the Secretary of State, is able to find a solution, she will have the support of Labour Front Benchers and, I am sure, Members throughout the House. We will offer our good offices to ensure that a settlement can be reached. There needs to be a proper and fair resolution.

2.15 pm

The Parliamentary Under-Secretary of State for Health (Jane Ellison):

.....

Having acknowledged that not everyone is satisfied—far from it—with the current system of support, it is extremely important to remember that the system makes an enormous difference to the lives of many beneficiaries. To date, more than £365 million in support has been paid to more than 5,000 people in the UK affected by HIV and hepatitis C and their families. Through the reforms made in January 2011, which some Members have mentioned, the Government have improved the system of support. Since they were introduced, more than £70 million in extra funding has been made available in England.

...

Mr Tom Clarke: The Minister will recall that my right hon. Friend the shadow Secretary of State made some profound comments about the role of the civil service in dealing with these problems. Will she take time to respond to them?

Jane Ellison: I have noted the comments of the shadow Secretary of State. I can only speak from my own experience and say that in all the ways in which I have wished to consider this issue—those have ranged widely over the past year—I have been ably supported by my civil servants. Ultimately, this decision is a political one.

.. In conclusion, I want to say that this was an utterly appalling tragedy, which has caused grief and sadness to many people and their families, as we have so often

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heard. The Government must do right by those people on whose behalf so many Members have spoken today. I will take away everything that has been said, and as long as I am in my current office, I will continue to work to bring to Parliament the conclusion that so many Members have said they want.

2.28 pm

Alistair Burt: I thank all Members who have spoken. What I am most proud of is my role in enabling this debate to take place, which has provided the opportunity for so many speeches. The best contributions were made not just by hon. Members, but by our constituents, because in very many cases we used the words that they have given to us so that we could be their voices. If memorable phrases from today's debate are remembered, they will be theirs.

……….

If the Government cannot respond before the election—as I made clear, I entirely understand and accept what the Minister said—then all the parties have manifestos to write. We could all put something in our manifestos that gives a clear commitment about what will happen should we form part of a Government in the future, and there is no reason why that should not be done with some degree of co-operation. Those who have been so faithful in pursuing this issue, in circumstances that we heard described today, will know that at last they have a Parliament that will no longer take no for an answer.

Question put and agreed to.

Resolved,

That this House supports a further review of the circumstances surrounding the passing of infection via blood products to those with haemophilia and others during the 1970s and 1980s; notes the recent report from the All Party Parliamentary Group on Haemophilia and Contaminated Blood into the support arrangements provided for those who contracted blood-borne viruses as a result; also notes that the Penrose Inquiry into these events will

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shortly be publishing its findings in Scotland; further notes that those who contracted viruses and their partners and dependants continue to be profoundly affected by what happened; therefore welcomes the Prime Minister's commitment to look again at this issue; and calls on the Government to respond positively to the APPG report and engage actively with those affected with a view to seeking closure to these long standing events.