

**All Party Parliamentary Groups on Carers; Dementia; Disability;
Equalities; Ageing and Older People; and Social Care
Joint APPG meeting on the Green Paper on Adult Social Care
Committee Room 8, House of Commons
4–5.30pm, Tuesday 7 July 2009**

Attendees: Joan Humble MP, Baroness Campbell, Jeremy Wright MP, Baroness Wilkins, Lord Rix, Edward O'Hara MP, Sir George Young MP, Kelvin Hopkins MP, Hywel Francis MP, Michelle Gildernew MP,

Apologies: Dr Brian Iddon MP, Ian Taylor MP, John Thurso MP, Ronnie Campbell MP, Dominic Grieve QC MP, Dr Alan Whitehead MP, Dr Liam Fox MP, Derek Conway MP, Lady Winterton MP, Dr Bob Spink MP, Lord Lester, Richard Benyon MP, Sir Nicholas Winterton MP, David Blunkett MP, Andrew Mitchell MP, John Hutton MP, George Howarth MP, Gerry Adams MP MLA, Sion Simon MP, Jim Hood MP, Gary Streeter MP, Jonathan Djanogly MP, Danny Alexander MP, Michael Ancram QC MP, Adam Afriyie MP, Anne Milton MP, Edward Timpson MP, Malcolm Moss MP, Robert Key MP, Andrew Dismore MP, David Laws MP, David Wilshere MP, David Gauke MP, Andrew Lansley CBE MP, John Randall MP, Gavin Strang MP, David Cairns MP, Alistair Burt MP, John Maples MP, Graham Brady MP, Anne Main MP, Laurence Robertson MP, John Gummer MP, Caroline Spelman MP, Adrian Sanders MP, Ann McKeichin MP. David Hanson MP, David Kidney MP, Richard Taylor MP, David Heathcoat-Amory MP, Rob Wilson MP, James Paice MP, David Drew MP, Robert Walter MP, John Healey MP, Peter Bottomley MP, Clive Efford MP, Susan Cramer MP, Tim Boswell MP, Dai Davies MP, Linda Riordan MP, Stephen O'Brien MP, Paul Rowen MP, Mike Penning MP, Ann Keen MP, Angela Browning MP, Dr Evan Harris MP, Sir Paul Beresford MP, Mark Durkan MP MLA, Frank Dobson MP, Maria Miller MP, Mike O'Brien QC MP, Tom Brake MP, Mark Francois MP, John Redwood MP, Dan Rogerson MP, Alun Michael MP, John Smith MP, Alistair Carmichael MP, Peter Hain MP, Michael Martin MP, Brooks Newmark MP, Greg Knight MP, Nick Clegg MP, James Brokenshire MP, Hugh Bayley MP, Eleanor Laing MP, Pete Wishart MP, Adam Price MP, Jim Cunningham MP, Anne Snelgrove MP, Bob Russell MP, Ian Lucas MP, Michael Jack MP, Jo Swinson MP, James Arbuthnot MP, Sir Alan Beith MP, Jon Cruddas MP, Anne McGuire MP, David Davies MP, Norman Lamb MP, Chris Huhne MP, Sylvia Heal MP, Mark Hunter MP, Peter Ainsworth MP, Stephen Crabb

MP,

Joan Humble MP (Chairperson for the meeting) informed the group of the agenda for the day and welcomed everyone. She introduced the speakers, Niall Dixon of the Kings Fund and Robert Droy from the Southampton Centre for Independent Living.

Niall Dixon thanked everyone for the invitation to speak. He said the case for reform of the social care system was well-known, there was mostly universal consensus that the current system of social care funding is unsustainable, which is an important word, because we are faced with a very different economic situation from the one in which when we published our report in 2006, and it is in need of urgent reform.

Niall said two important things had happened since then. Firstly, many older people and adults with disabilities as well as their families and carers are being failed now than they were in 2006; the system has deteriorated over that period. Secondly, the government has run out of money. So we have a situation where we have a system that is not coping with levels of need, which is universally regarded as unfair and over complicated, and is not doing what it is supposed to do.

Niall said by 2025, there will be very large additional numbers of people over the age of 65 and the number of people over 85 will have increased by two-thirds. That is something we should celebrate. That people are living older. But for a while we believed that the extension of life would mean that people just lived longer and then had the same bit of unwellness of either dependency at the end. But we now know, that not only thankfully are we getting more healthy life years, but we are getting more unhealthy ones as well.

Niall said this means that the system that is not coping now, if we do nothing will cope even less as we go forward. Niall said he was unclear where the opposition parties, in particular the Conservatives are on this issue and his question to them was is this in the too difficult to do box? Or is it as someone has said – and this is not entirely cynical - that there are things called Wednesday policies and Friday policies. The Wednesday policies you talk about before the elections and the Fridays are after. This has to be a Wednesday

policy, this is an issue that needs to be discussed and debated in the run up to the election.

Niall said he did not think it was a sustainable position to hope that it will be a Friday policy; we absolutely need to bring social care out of the quiet position that it has been in.

Neil said he thought there is a policy and politics issue and it needed to be separated out. The policy issue is clear. It is an unsustainable system so we have to find a new system and we have to come together and agree that. Niall said he hoped the politics gets aligned, because the worst result of this would be a slinging match between the political parties in the run up to the election which is the same as kicking sand in the face of the voters, because they will not understand what the issue is about.

Niall said there are some issues he hoped the Green Paper would address but there are also some key tests to measure the green paper against. The first is financial - the amount that people pay for care, either as taxpayers or individuals, contributing to the cost of their own care should relate to what they can afford and take into account their overall income and wealth.

Niall said secondly equity of access. People should have broadly similar access to the same level of support, based on their needs and circumstances, without being disadvantaged by virtue of their age, type of need or other circumstances.

Niall next highlighted geographical fairness. The help people receive should be based not on where they live, postcode lottery, but on what they need. Avoiding some of the variations that currently apply. The government has dropped hints that they are in favour of some form of national entitlement and that is something we would really welcome that is absent now.

Niall said there is the intergenerational question; a new system needs to balance the contributions. We do need to sort out the generational contract which is very different from 1945, when older people in particular, lived a very short period of time, generally lived with their families, and where we did not have the kind of needs which need to

be met today.

Niall said it was important to solve the national local divide and really get to grips with it. Niall said he did not think the work that they did in the caring choices coalition indicated that people were willing to accept, particularly older people who had wealth and so on that they might make a contribution. What they didn't want was a system that simply exhausted them, exhausted their carers and exhausted their wealth and then said "Oh well, we might just come in and help you now!"

Niall said there needed to be a good, solid national debate where the issues are honestly discussed, and if we can't have everything tomorrow, we should have a very clear plan about when we are going to have it, there is some remedial action that needs to be taken to improve the system now, even if it takes a longer period of time to reach that intergenerational settlement, or indeed to enable people to build up whatever it is that they need in order to provide for their social care in the future.

Robert Droy thanked the group for the invitation.

Robert said he works for Southampton centre for independent living and they were celebrating its 25th birthday this year, and it is quite important that we remember that a lot of the work that we are talking about today has actually been done over the last 25 years by centres for independent living. We have literally empowered thousands of disabled people to actually take choice and control over their lives.

Robert said all the control and quality issues are all very worthy aims but what we really need to look at is how are we going to ensure that it happens in practice. Not just for empowering disabled people, like some who are in this room today, but actually for the disabled people who are socially isolated and maybe don't know about their legal rights and their legal entitlements. How are we going to make sure the policies that we put in place today actually have a real affect on their lives in the long run?

Robert said centres for independent living have been at the forefront of developing the agenda starting with direct payments and now

moving towards self directed support and individual budgets, and it is very important that centres for independent living have always worked in partnership with other groups, such as carer groups and other equality groups.

Robert said they come together to really provide a united voice to tell government what we want and what we don't want on our social care system. Robert said he believed that everybody, regardless of their age or impairment, should be able to have choice and control over the support they receive. This is not about being good to disabled people; it is actually about basic human rights, and it is not just about getting up in the morning and going to bed at night - it is actually about disabled people participating fully in all areas of life, and living a full and active life - and it is important that it is disabled people and older people who actually define what their needs are. It is not for other so-called professionals to decide what they think we need - it is actually for the service users themselves to decide how they want to live their lives.

Robert said human rights cannot be at the whim of the local authority; it is really important that we are guaranteed minimum entitlements wherever we live in the country. Support has got to be portable so that people can move around the UK and they can move across Europe, if they want. There are a great number of disabled people who feel they can't move to a different area of the UK to take up employment or to be near their families because they are worried that they will lose the support that they have fought so hard to achieve.

Robert said social care must be seen very much on an equal footing with health care. It makes no sense that we pump millions and billions of pounds into the health care system and then just leave social care to almost get on with it. Lack of investment in social care will cost more in the future, and there are a lot of policy documents and a lot of pilots promoting preventative work, but actually that ever tighter eligibility criteria that a lot of local authorities impose leaves increasing numbers of people, particularly older people, at risk of developing more serious impairments, higher support needs and at the end of the day, in purely economic terms, that will cost more in the long run.

Robert said it was necessary to look at how we support people who are going to fund their own care in the future. There are increasing numbers of self funders who get no support whatsoever from the government, and we need to look at actually how we can support them and that we need to look at whether the charging policies that are in place for social care are really fit for purpose, and whether they really do deliver better outcomes or whether they are just actually a cap on disabled people and drive disabled people in to poverty.

Robert said with regard to advocacy, support, information, particularly peer support, it is essential to ensure all users can take full advantage of this personalised agenda. What people do not want to see is a two-tier system where we empower disabled people who get what they want, but dis-empower disabled people who don't get the same rights and entitlement's so we need to make sure there is funding for advocacy services and peer support. This can be best delivered by actually promoting centres for independent living, based on the model that places like Southampton centre for independent living have developed over the years.

Robert said many centres for independent living have fallen by the wayside, and mostly because they have had to compete against some of the bigger organisations that are not user-led. Local authorities feel compelled to say that it is compulsorily to competitively tender for many of the support services that we all know, and to be honest the Local Authorities know, would be best delivered by local disabled people working out of centres for independent living.

Robert said the two messages he wanted to leave everyone with are that disabled people receiving the correct support in order to live a full and fulfilling life is a human rights and equality issue and it is really important that we see it in terms of giving people their human rights and protecting their human rights, and also the fact centres for independent living need to be supported to empower disabled people to take full advantage of the personalised agenda. Policy does seem to be going in the right direction. However, it needs to be implemented at a local level in order for it to be really meaningful to disabled people living their every day lives.

Joan Humble MP stressed that the meeting was a joint meeting across the all party parliamentary groups on Carers, Dementia, Disability, Equality, Ageing and Older people and Social Care. Joan highlighted the presence of Parliamentarians from the different all party groups.

Lord Rix said he raised the issue of the availability of changing places toilets with the government but was told a final answer would be available in 2013.

Edward O'Hara MP said he agreed with Lord Rix on this issue.

Joan Humble MP said for many people with a disability, or children with disabilities it is the concrete examples that make a difference to their lives, and having appropriate changing facilities is a key one.

Baroness Campbell of Surbiton said she was particularly excited about the portability side of the paper, because the rights to move across the country and keep your support the same and take it with you is a very important human right, to look for work, go and live with your family and so on, so this was a very important issue.

Baroness Campbell said she wanted to ask both speakers on the issue of invest to save, because we have one political party talking about potential cuts, and of course we have the current government talking about investing in order to empower people to take more responsibility over their care and health.

Baroness Campbell said part of that is allowing that you have got older people and younger people who use social care, and one thing that was a small victory for disabled people who used social care was keeping their earnings out of the charging policy.

Baroness Campbell said she wanted to know what both speakers thought about this issue of when we talk about equity of access, and equity of use and equity of charging, but actually we are not equal, are we? When you are young, you want to go to work and you want

to save for a family and enjoy the fruits of your labour, so therefore, do you expect the old and young to pay the same for their assistance in this invest to save environment?

Niall Dixon said first of all, on the issue of invest to save there needed to be absolute honest about the finances. Niall said he did not think that the political class at the moment particularly want to tell it like it is.

Niall said the post 2011 current comprehensive spending review runs out, and possibly before the other government comes into ram on the brakes, there will be a jamming on of the brakes. The question then is there is still going to be public spending and where is it going to fall and how is it going to be distributed? The conservatives have said they will protect health, by which we hope they mean health and social care; and to be fair, they may have said that, but the health bit is the bit we have certainly heard. Likewise, Labour has said, too, that they will try and protect.

Niall said the reality is that even if you 'protect' health, the kind of funding that health has been used to over the last 7 or so years is not sustainable and will not be sustainable going forward. The kind of growth that they might be talking about, which is very, very low growth, will cause the Health Service itself to either increase its productivity and do things smarter than it is currently doing, some of which is possible, or it will have to reduce the offer of what it is about, so that is the reality of health care.

Niall said one of the things you could do is put social care in with health. Now some people have said in the past if you put them together the social care will be lost, but actually you might quite cleverly - because social care is the smaller element - it might benefit from some of the huge sums that go into health care anyway. Therefore, there is a possibility of social care doing better than health in the coming years, and it needs to do better than health, because the situation is so difficult.

Niall said with regard to the invest to save argument - which the Treasury has always been very wary about because they always hear the invest bit but never seem to get to the save bit - and of course it is

true that there are ways in which we could, not least if we managed and supported older people with long term conditions more effectively, at an earlier stage in their progress of their illness, as it were, then we would, manage to prevent lots of unnecessary hospital admissions.

Niall said we know that hospital admissions cost huge sums of money to the system. There are examples where we can work smarter, and some of that is about supporting people more effectively in their own homes, which does coincidentally tie in very much with the more modern agenda of maintaining peoples independence and giving individuals control over their own care.

Niall said the short-term difficulty would be actually just having the size of budgets that are needed in order to bring about these changes.

Niall said there is something different about someone who has lived the whole of their life, who has built up considerable assets and so on, and who then finds that towards the later bit of their life that they have a degree of dependency. There is something different about that and what we need to do about that in terms of this society, compared to somebody who is young and disabled and is earning – the issue is how we untangle these matters and deal with them in a fair way.

Joan Humble MP said in order to invest to save, you need the structure to do it, and of course the government has changed local structures through local area agreements and introduced pooled budgets, shared budgets, across health and local authorities, local councils, and we now have, or are moving towards multi area agreements across several local authorities. In that context would there be more opportunities to invest to save, so that health and social care especially and health and children's departments in local councils can have schemes where the Health Service will invest in a local authority initiative on the basis that that will in turn save them money?

Niall Dixon said the history of this is very patchy and mixed. If you look back, people have been attempting to do this for the last 30

years, and there have been fantastic schemes and there are examples where it has worked. What we haven't got is something that, if you look at somewhere like Tore Bay, it has been really successful and they have brought together people delivering services jointly on the ground and they are able to pool budgets. What we have not got is a single model in order to be able to do that, and we need to revisit it. We do need to revisit the divide between health and social care and find a more imaginative way forward.

Robert Droy said if we really believe that social care and people having a pool to live independently is a human right then actually charging people to maintain their basic human right cannot be fair.

Robert said you then have to go on to the next level and actually say how can we do wider work, particularly around promoting employment around disabled people . . . there is a balance particularly for this generation that we want to provide social care basically free at the point of delivery so that the whole of the nation shoulders the responsibility of funding social care, just like they do with health care, but at another level we probably need to look at how we can promote more employment for disabled people, getting disabled people out of poverty, improving educational opportunities for disabled children

Robert said hopefully in the next generation, or the generation after that, disabled people will be on an equal economic footing and again when that happens, then it may be easier to actually start looking at how we fund the social care system. The core bit is really saying that actually we can't see why health care and social care is any different and actually the fact that people may need care in their own homes – why is it that you had to supposedly pay for that, whereas the minute you go into hospital that support you need suddenly becomes free of charge. There has to be some debate around how that is going to be justifiable in the long run.

Jeremy Wright MP said he wanted to talk about the interface between the health and the social care system. It seems that one of the problems that we have is there isn't enough sharing of information. You come across too often needs assessments being done in hospital and needs assessments being done by social care

organisations, and the two not being shared elongates the process in an unnecessary way.

Jeremy said he had some concerns and he was sure others do. One of the concerns is with those who don't want as much freedom as they are being offered under direct payments and individual budgets and want some help administering them. The danger is that we have some local authorities are either saying "You have all the money, here it is get on with spending it" or saying "We will do it all for you" and not much in between. There needs to be in the Green Paper or elsewhere an understanding of how to provide a menu which is a la carte and you can have as much help or as little as you need administering the money.

Jeremy said he also wanted to raise the issue of workforce training. There are huge issues about the social care workforce, raising the esteem in which those people are held so we attract good people and keep them, but what is worrying slightly is that we have come to the conclusion as far as dementia care is concerned that there must be more dementia care training for those who provide dementia care, but it would be good to hear Roberts view on how that conflicts potentially with the freedom to choose the care you want from the people you want to provide it.

Jeremy asked is there conflict between giving someone the freedom to say "I want this individual to provide the care in the way that I want them to do it" and on the other hand, being reasonably prescriptive about the type of training the person providing the care needs to have, or is there a fundamental amount of training that everyone needs to have before you let anyone make any choices about who provides it to you.

Robert Droy said on training, a lot of the training needs to be more around 'are they coming from the equality viewpoint'? Do they actually really understand the choice and control and equality issue? At the end of the day, you can then train people in things like how to handle somebody with dementia or how to do moving and handling training.

Robert said the point is accepting the right kind of people who can be

empowered to take encore training, for some people there will be optional add on training that people may or may not want to take on, but it was worrying the idea of having minimum training standards, because some of the best Personal Assistants are actually people who have almost fallen into it by accident.

Robert said he actually took on someone who had been made redundant from working in a garage and they said, "I have never done this type of work before, but I will give it a go to help you out", now he has become a PA for several different disabled people and he is learning all the time. But if you had actually said to him that you have to go on some kind of training course before you can even begin to be a PA, he probably would have said oh no, I am not interested in that.

Robert said it is about how we do train social care staff up, but how we do it in a way that doesn't become restrictive and doesn't actually put off the very people that we want to get at, people who actually genuinely believe that disabled people and older people have the option to live in this community and actually want to empower them to do that.

Joan Humble MP said this issue was raised in the All Party Dementia Group's report. Also a few years ago the social care group did a report on the challenges facing social care staff, and we looked at how through individual budgets people were employing those who were not traditionally part of the work force. And it is trying to have a compromise between having trained staff in the larger scale organisations and then acknowledging that there will be staff being employed through individual budgets that have not had that traditional route of training but to make sure that they never knew less about how to do the job that they should be doing.

Ashok Ghose from Asian People's Disability Alliance said when we talk about care we always seem to give the impression that care is a form of burden. You see, and that all those who need care are economically not viable and therefore it will continue forever. Ashok said we should look at the situation in terms of enabling people to be fully empowered so that they can participate fully.

Ashok said what is important is what the needs of individuals are. People will tell you exactly what they need and therefore the approach required is a user-led approach that will help people participate more fully. Our approach should be that we ought to make all people completely part of society, so that they can make their contributions to the economy.

Niall Dixon said the fact is that if you introduce a direct payment, rather bureaucratically, or individual budgets or you just hand out Visa cards, if you are doing that you have to accept that people make their own decisions they make choices and the choices may not be the ones you agree with.

Niall said at the same time, there are people who need support and help and some people need more support and some people need more help in reaching those decisions, and if we are going to change the mindset, we have to go into that mindset and say "Actually users will have control and choice".

Niall said people will be at various stages, and people may be at a stage in their dementia for example, where they are not able to make decisions for themselves, then you have to have arrangements, in which you either find out what they would have wanted from the past and there are ways in which you can do that increasingly, but it is about trying to keep people as healthy as possible.

Niall said you couldn't keep them absolutely healthy. Try to keep people as independent as possible - there is nothing wrong with dependence, we are all dependent on each other in different ways but people want to be as independent as possible so. We are only beginning to understand what is possible if you hand over control.

Julie Jaye Charles from Equalities National Council said firstly, not to put down the APPG, but that she is the CEO of a user-led national organisation developed across 9 regions and she sitting there having 15,000 members on her books, BME disabled people, and her organisation has never been invited to actually speak at one of these meetings and it is a great shame that the head of the equalities APPG is not actually here today because equalities actually

covers all the diversities of carer dimensions.

Julie said it is more than looking at disabled people as not a homogenous group and what we have here, you are talking about the basis of disabled people really as white disabled people, because that is who you are and but she was coming from a different perspective, she was not afraid to say that there are communities, thousands of communities that are not accessing services and certainly won't be accessing or even know about a Green Paper, and it is down to organisations like Equalities National Council to actually work with them - advocacy is a key, key area.

Julie said there is a huge gap in social care and health care provision, advocacy services not being available and there is a lot to be done within the Green Paper about the commissioning side of when money does go to PCTs, local authorities, et cetera, there are policies and legislation that say that they have to work with community organisations user groups, and different organisations on commissioning. That isn't happening. What also isn't happening is around the recommendations that people make from their equality impact assessments, the Green Paper has to be really strong on making sure that it does tease out local authorities, PCTs and Strategic Health Authorities that are not meeting their own requirements in their equality impact assessments.

Julie said there was continuing development across the 9 regions, we already have 33 national ambassadors who are going to be working with organisations of BME disabled people, and it is really important that when you are talking about disabled people, that you are reaching those that really, really are on the dirt bottom, not just those who know what individual budgets and what the personalisation agenda is, but also people that don't actually know who you have to reach out to.

Julie said when you talk about the communities getting older the higher percentage of those communities that become older are going to be BME elders that are not going to be going back to the Caribbean or Africa or where they are from because they can't afford to do that, so they are going to be in need of more care. They already have to access a lot of dementia care, things around heart disease,

but we are not doing anything that is actually focusing on specific communities and that is where we really are going wrong. You have got to focus in on communities and not just take it as this huge group of 'disabled people and that everyone accesses CILs, because they don't.

Claire Helman from Winvisible for women with invisible disabilities said they were also a multi racial group. Although there are a lot of people needing health and social care, those of us who are black and immigrant are seen as deserving less than others and have discrimination in the assessment system, and those of us who are seeking asylum, have little access to services because we are only seen as here for a short time and not staying permanently.

Claire said the climate that we are encountering is one where your life is only valued while and if and when you work, and it is true with the Welfare Reform Bill when the government is planning to abolish income support which gives you benefit eligibility based on need and they are changing that to work conditions and job seeking as a condition of getting benefit, and with unwaged carers they want it both ways.

Claire said they want carers to provide 87 million pounds worth of unwaged care per year and they want carers to be job seekers at the same time. It is disabled people and older people who are going to lose out on that. Most users of home care are older women who have worked their whole life, worked unwaged, bringing up families and looking after communities, and who have paid national insurance contributions. We have paid council tax and VAT and we are paying in lots of other ways and it is very frustrating to have this discussion about future planning because we know that the situation is very urgent with a lot of people not getting any help whatsoever, who have dropped out because of charges or who are not getting services because of the rationing which the Telegraph has exposed recently, and other media have exposed too.

Claire said something needed to happen immediately with regard to what is happening to people because people's lives are being cut short at the moment. As an example, Winvisible is helping a couple aged 96 and 95; they had a small amount of home care, a couple of

calls per week. Then they received a bill from Camden council, for 1,500 pounds out of the blue, which they weren't expecting. They contacted the council and were told either they go through a humiliating means test, or, if they didn't want to go through the testing they would have to pay 13 pounds an hour, which is the rate that you pay when you don't want your means to be assessed. They decided if that was the case then they did not want it.

Claire said no one at that stage looked at their welfare, how they were going to manage and luckily we found out about it, because the wife was ringing around trying to find a free shopping service and that is how we found out about it. We wrote straight away to the Council and said "You have to reinstate their service immediately, without assessing", the policy makers here really have to take that welfare very seriously. There is plenty of money around for the banks, for Trident, for Afghanistan, for Iraq and so on. Why shouldn't they be investing in caring not killing? It has to be about priorities and across all policies not just social care.

Anna Young (individual) said what is missing with the Green Paper and the personalisation and direct payments is when things go wrong and you have actually got vexatious litigants out there. That really causes concerns so there needs to be a very robust system in place for councils. Each council is different from one council to the next council. Anna said in her case, she was taken to an industrial tribunal because she was awarded ILF, Independent Living Fund, her PA became obsessed with her; became intrusive and there doesn't appear to be much infrastructure where actually things go wrong.

Anna said she was going to be placed on the personalisation test bed and but there seemed to be a lack of knowledge where councils are concerned and where Social Services and social workers were concerned. Only 17 per cent of social workers actually know about personalisation and the new agenda. Anna said she was worried about when things go wrong.

Niall Dixon said he didn't know the detail of Anna's particular case but it illustrates the point that overtime, for example, without necessarily going into the 'everybody needs to be trained to this standard' you might have people who are accredited and it would be

good for personal assistants if they had that kind of system, as it were, and then people who were starting out and want their first PA could go to people who had been through some kind of process

Anna said she was very interested in safeguarding, it is very hot on the agenda at the moment, and she was accountable for herself but she could not be held to account for someone who chose to do harm to her.

Mike Stallard from the Met Police Carers Support Group said he came from a very small area of the green paper, which is the working carers side. He said he was a police officer and had been so for 30 years.

Mike said three years ago, he set up the working carers group. Mike said they put out calls for people who were interested in speaking to them, and had over 450 working carers almost immediately contacted them with some kind of problem they had.

Mike said they were seen as best practice, the way they set policy. Mike said he was involved in this, and within the police how we support the working carers there - still there are serious problems. To write a policy document is a fairly difficult intellectual task, but to actually ask a manager to implement the policy is very difficult for them without support and training.

Mike said we have got to start at the top with the senior managers and businesses. We have to get an acceptance of flexible working practises; the prospect is government figures of 13 million working carers in the next 10 years! This is going to comprise of our most skilled and experienced people and unless businesses both private and public, open their minds to embrace new working practises, they are not going to survive. We need people to assist businesses in getting working carers.

Mike said they have it now even in the police, a very robust policy that is robustly looked at and made sure it is working, they still treat people badly because they don't understand. Once they understand, it is about how they change. This is what we have to put into businesses. Mike said they were talking to a wide range of

businesses and organisations.

Joan Humble MP said last August the Work and Pensions Select Committee produced a report on carers and there was a section in that on working carers.

Robert Droy went back to the point of Julie Jaye Charles as it was a very important. A lot of disabled people not only experience oppression by being disabled, but because they belong to a black or minority ethnic community, or they may be gay or lesbian, or be from a different group. It is important that we take those issues on board.

Robert said centres for independent living generally need to do a lot more work around how we become more culturally diverse and appreciate the things that these communities have and we are doing work with gay and lesbian disabled people at the moment, and so there is a real issue for disabled people who feel not only discriminated against because they are disabled but because they experience multiple discrimination because they also belong to a minority group.

Julie Jaye Charles said it was not just about social care. The majority of people in prison from BME communities have mental health difficulties and a different pathway for them back to work when they come out of prison and this lands on the PCT. It is not just about social care; it is also about housing, employment and education.

Geoff Finister from the RNIB raised the question of attendance allowance and how can we ensure that this very valuable entitlement driven non-means tested social security benefit doesn't become a discretionary cash limited means tested payment hidden behind every local authority rationing criteria.

Robert Droy said the issue about how we integrate all the different funding streams together and make sure that basic entitlement don't end up getting wrapped up in complex eligibility criteria. Things like the eligibility criteria for the Independent Living Fund are incredibly discriminatory particularly to older people who can't even get Independent Living Funds, and it seems astonishing that nobody has actually taken that Independent Living Fund to court over that,

because surely, any more blatant exhibition of age differentiation is there. We need to be really careful that when we are integrating these funding streams we don't end up almost shooting ourselves in the foot and making it harder for people to actually get almost automatic benefit, and making people having to go through even more hoops. We would all like to see some kind of national minimum entitlement, some kind of minimum entitlement that people right across the UK can access without necessarily having to be exposed to the postcode lottery.

Jeremy Wright MP said we have to be very careful that the invest to save slogan means what it says and we don't end up in a position where we make a false economy and if you are talking about attendance allowance, you are also talking about carers allowance in the same way - there is a danger that we end up with a position where the carers who we know save the state a massive amount of money in providing unpaid care decide that they are unable to carry on doing so, for whatever reason, and the burden then passes back directly to the taxpayer with a greater expenditure, so we have to be quite careful in making any savings that we don't end up incurring greater expenditure. We need to have a good look at the cliff edge that comes when people retire on their carers allowance and have a look at whether we should continue that to make things a little easier for people to carry on what they are doing and saving us all a great deal of money.

Joan Humble MP encouraged everybody to look at the Work and Pensions Select Committee report on Carers.

Joan Humble MP informed the group that the Minister could no longer attend as he had been called away.

Andrew Chidgey from the Alzheimer's Society said there is a risk that we all need to guard against in terms of the level of ambition and what we are trying to achieve through the forum, because we are looking for a long term settlement that clearly spells out how we can support people better in the future. Of course we have to be mindful of the circumstances in which many people and communities are.

Andrew said we have also got to be very ambitious and again still

waiting, it is waiting for things to come, one of the things that people with dementia and their carers are waiting to see is are the plans going to be ambitious enough to be able to really deliver the type of care that we want, the spin and rhetoric is about who is going to pay and that is the nub of the issue, but people are worried about what they are going to get not just who was going to pay.

The other thing that people with dementia and their carers are saying, Andrew said are we going to see a solution that doesn't just cover cost of care that might be thought of as personal care costs. Are we going to see solutions that recognise the breadth of costs that people face because of disability? The attendance allowance point is very well made. When we have done survey work and group discussions with people, people are very resistant to tinkering with attendance allowance because they don't believe any assurances that are given that they are actually going to get a better system.

Lord Rix said there is an absolute logjam at the moment, we are all on the same railway line because you have the Welfare Reform Bill, you have got the Green Paper, you have the apprenticeship, skills, children bill, you have the equality bill coming along as well. You have so much legislation coming up at the end of this particular parliament and it is absolute madness. Lord Rix said he had a horrible feeling that the welfare reform bill and the apprenticeships bill won't even get out of the committee stage before we go into recess, and it will come up again in the Christmas time, or in the wash up time in October. It is ludicrous at the moment, the way that the whole of this legislative programme is literally crashing to the buffers at the same time.

Niall Dixon said it has been a really interesting discussion and amazingly good considering we didn't have a Green Paper to actually discuss! There is still a worry about the Green Paper appearing and then disappearing and there is something about keeping the debate alive, trying to keep, dare I say it in these rooms, the politicians honest about what the debate is and what is realistic and holding politicians to account. They are not going to legislate on this side of the election. No one is expecting that, but what we do expect and should expect is an honest debate going forward and in the manifestos a clear commitment about what they will do the other side of the election.

Robert Droy said it really is important that we all work together, because at the end of the day a lot of us in this room, carers and other equality groups, disabled people, we are all roughly saying the same thing even though we are coming at it from a different angle and what would be the worst thing too is letting in fighting and factions break out when actually we have a really good chance with the green paper of actually all coming together, and accepting that we may have different points of view, but coming together on the things that we do all have in common, and really holding whatever government is in power after the election to account and actually saying "Come on! Lets actually get this sorted out", because otherwise we will just have more policy documents that clutter up all our book cases but actually don't make any real difference to disabled people on the ground. It is not about what we all think in this room, it is actually about are disabled people and older people living in their own home going to be any, not better off, but any freer or more supported in two years time than they are now.

Joan Humble MP thanked everything for such a stimulating debate and thanked Parliamentarians from the different All Party Groups for attending.

Joan said all of the different all party groups are looking at different aspects of this key debate and we do need to work together and the details of what has been said today, notes have been taken.

Joan said she would make sure the minister gets an account of the discussion. She will follow up with him the timetable for the publication of the Green Paper, highlight the key issues that have arisen, not least that we do know what good practice is in social care, so we ought to learn from that good practice.

Joan said we need to look not just at those people who are looking to the social care system to pay for their care, but also the people who have currently paid for themselves, the self funders, and make sure that they understand what is happening.

Joan said we need to look at the role of local authorities and the wider local decision makers through the local area agreements and multi area agreements so that it is all the agencies both statutory and

voluntary, working together, and then of course the key issue is who pays and that is the bottom line.

Joan said we had the White Paper 4 or 5 years ago called, "Our health, our care, our choice" which was an excellent document that said a lot of what people in this room have been talking about. Yet we are now going to a Green Paper to go back to principles and ask questions. We must have the debate; we must not let it slip back. The equalities bill is actually a key part of this jigsaw.

Joan said the key issue for politicians is whether we move ahead with consensus or whether there are genuine party political differences. We had an example of all political parties working together on the pensions debate, where the government very, very carefully built up a consensus over a 4 or 5 year period, because we knew that we were legislating for 25, 30 years, so whichever government is in power people needed to know that the pension system was going to be safe for the next 20 or 30 years. The question now is whether the social care system will be safe for the next 20 or 30 years.

Joan said there will be areas where we can proceed together in all party agreement but there may well be areas where there won't be and in which case, that is going to be an interesting discussion in the run up to the next General Election.

Joan recommended that there should be another follow-up joint meeting in the autumn, involving everyone, by which time the green paper will be published and the agenda can really move forward. Joan concluded the meeting.