



RADAR briefing:

The Green Paper: Shaping the future of care together

- What it says and what we need to do

1. What does the Green Paper say?

The Government published a Green paper (consultation) on 14 July setting out a vision for a new care and support system. It highlights the challenges faced by the current system and the need for radical reform to develop a national care service that is fair, simple and affordable for everyone. It wants to know our views by 13 November. Everyone is encouraged to get involved – it's a massive issue that affects us all. The key proposal is for a "National Care (sic) Service in England". In this new national system anyone using it should be able to expect:-

- **access to prevention services**
- **a national assessment – you can move without getting re-assessed**
- **a joined-up service**
- **appropriate information and advice**
- **personalised care and support**
- **fair funding.**

The 3 really big questions the Green Paper asks are about funding the new system:

1. The Green Paper asks whether there should be a fully national system or whether we should have a part national/part local system where local authorities still have a lot of leeway in terms of what they provide. Under a fully national system, Government would decide how much funding individuals with particular levels of need should receive. There could be adjustments to take account of regional variations in cost. On the other hand in a part-national, part-local system the amount of funding available to individuals would be set locally.
2. The Green paper asks people to choose between 3 different ways of funding care and support: the partnership, insurance or comprehensive models

On funding the Government is not really worried about how much it costs to support under 65s – it's the big explosion of over 65s that worries them and how their support needs can be paid for. They rule out just funding older people's support needs from general taxation for the simple reason that soon there won't be enough people of working age and paying taxes to foot the Bill (fair enough!). So the options they propose are:-

- A partnership model, in which everyone who needs support would be entitled to state support for maybe a third or quarter of the cost – how much you get would depend on a means-test. People could end up having to pay £20,000 or £22,500 out of their own pocket. Many people would pay much less. And some people who needed high levels of care and support would pay far more than this, and would need to spend their savings and the value of their homes.
- An Insurance Model under which everyone would be entitled to have a share of their care and support costs met, just as in the Partnership model but where the state would work with private insurance companies or set up its own scheme, into which individuals could pay in return for their care costs being met if they need care and support. The individual's

contribution could be made as a lump sum or by instalments before or after retirement, or via their estate after death. It would cost people around £20,000 to £25,000 to be protected by an insurance scheme.

- A 'Comprehensive' Model in which everyone over retirement age who had the resources to do so would be required to pay into a state insurance scheme (you'd need to pay between £17,000 and £20,000). Everyone who was able to pay would pay their contribution, and then everyone whose needs meant that they qualified for care and support from the state would get all of their basic care and support for free when they needed it. The system would need tailoring so as not to penalise the less well-off. People could pay in a number of different ways – by instalments before or after retirement or if you have a house you can pay when it's sold after you've died. With this model disabled adults under retirement age would get fully state funded care.

3. The Green Paper asks if people think Attendance Allowance should be scrapped to help pay for the changes.

Attendance Allowance is for people who are over 65 and need help with extra costs relating to disability. There was some talk that the Government was looking at getting rid of Disability Living Allowance too.

2. What does RADAR think about the Green Paper

The vision set out in the Green Paper draws heavily on all the things disabled people have been arguing for years: that we need portable support, choice and control and so on. The problem is it's not clear how the Government thinks we can get from vision to reality. The reality out there for many people seeking social care support is pretty bleak. Everyday we hear from people who are turned away from social services, driven into poverty by charging or treated with outrageous indignity and disrespect. It's obvious that radical change is needed and that legislation is needed to deliver that – but not any old legislation. It needs to be legislation that we shape and that is rooted in our human rights.

Some issues are still up for grabs – like whether we should have a fully national system or a lot of ‘local flexibility’ and how support should be funded in future. So we need to decide exactly what we want and press hard for it.

❖ **Yes to choice, control and personalisation**

Disabled and older people are the experts in our own lives. We are fed up of being treated with disrespect and often contempt by those who are supposed to be supporting us. Time to legislate for our rights to decide how we spend the resources we are entitled to. There are lots of different ways people can get in control – not just direct payments. But for people to be really empowered we need strong Centres for Independent Living we can turn to for practical support and guidance about how to manage direct payments, support for being an employer. We need independent advocacy and quality advice about support options – including peer advice. The Government said there would be Centres for Independent Living in every locality by 2010. They are way off target and there’s no funding to make this a reality.

We need legislation to bring about the big shift in power the Government wants to see, otherwise too many local authorities will find ways to deny us our rights.

❖ **Yes to information and advice**

But we want our user-led Centres for Independent Living too! The Independent Living Bill has proposals for rights to accessible information and advice – this is another thing that needs to be legislated for.

❖ **Yes to a national assessment and to portability**

To end the post-code lottery in independent living support we should end the days when your local authority gets to decide who to support and how. Disabled and older people must have clear rights to independent living where-ever they live. Plus people must be able to move from one part of the country to another without having to be re-

assessed and certain that they'll get the same deal wherever they live.

But a national system will only work if it is rooted in a framework of enforceable rights to support and clear guaranteed entitlements.

The new system must deliver more than the 'wash and feed only' approach many experience today. People need to be supported to live a full life and enjoy their human rights, that means rights to support to:-

- Take part in work, learning, sport, cultural and public life
- Fulfil our roles as husbands, wives, partners, parents and grandparents and have a full family life
- Socialise with our friends and make new ones

It is also vital that individual budgets are set at a level enabling disabled people to give decent rates of pay, training, holidays and pensions to PAs and support workers.

❖ Yes to prevention – but Government should be clear what they mean

The Green paper is vague and woolly on prevention – forms of support that help people stay independent and stop them needing more intensive health and social care.

We think prevention should mean:-

- People categorised as having needs which are 'moderate' or 'low' being entitled to state support to maintain independence and have a life.
- People with mental health issues having a right to early support and treatment
- Removing the means-test for Disabled Facilities Grants – there is reams of evidence of how cost effective adaptations are and how they prevent higher expenditure in other areas, yet many people we know can't afford to cough up for their share of the costs.
- Making better use of adapted or accessible properties – with Disability Housing Registers

- Speeding up the introduction of Lifetime Homes Standards across the private housebuilding industry and ensuring enough wheelchair accessible houses are built to meet the huge unmet demand.

❖ **Yes to joined up support**

If we want social care, continuing health care, adaptations, equipment, employment support and education support to be joined up then we need to pass legislation to integrate those funding streams and force different public bodies to cooperate to do that. Just leaving it to public bodies' discretion is useless. People must have one assessment for independent living support that leads to an individual budget covering all the funding available to them. We call it a 'one stop empowerment shop'. We waste millions on fragmented services and endless assessments for different agencies.

RADAR is backing an amendment to the Right to Control provisions in the Welfare Reform Bill to ensure social care funding is explicitly included in that new system (currently it is excluded although Government says the intention is to align it!). If the Government is serious about joining up they should support that amendment promoted by Baroness Campbell of Surbiton.

❖ **Yes to a national funding system**

National Government must decide what individuals will get – if we leave it to local authorities they will spend their money on anything but independent living and we will never get rid of post cost lotteries. Funding for independent living must be ring-fenced.

❖ **Yes to free universal social care**

We don't have enough information really to be able to say: yes this is the system we must have. We can see you can't meet all the future costs just out of taxation. The 'Comprehensive' option appears to be the only funding option on the table that would give people free social care at the point of use. Phil Hope the Care Services Minister keeps saying: if you want universal free social care go for the comprehensive system. So at the moment it seems to us the best

option to support and develop. There would be an end to charging and means-testing of disabled adults up to age 65 and they would not be required to make payments into the scheme (we think) – hurrah! The tricky thing is to make sure the system works fairly for older disabled people over 65 who don't have an 'estate' to offset their payments against and who are on low incomes. We are fed up with people on tiny occupational pensions getting bled dry.

❖ **No to scrapping Attendance Allowance or DLA**

RADAR is opposed to scrapping vital extra-cost benefits. These benefits are to help meet a wide range of extra costs not just care, but extra heating, laundry and so on. Take them away and people would lose choice, control and independence and more people would fall into poverty. If the Government were to set up the rights-based legislation we want and extend support to all who need it, then we might be able to have a sensible conversation about how extra costs benefits are paid to individuals. There will always be a need for payments towards extra costs above and beyond practical support and these should reflect more the real costs we face.

Government could save money to invest in independent living by making it easier for people to get DLA and AA, getting more decisions right first time around (why do we waste millions on paying private companies with zero disability awareness to make ill-informed assessments for benefits?) so we don't pay for so many appeals and reviewing people less frequently.

Other key points

- ❖ The Government has committed to setting up a 'national leadership group' made up of individuals and groups with expertise and experience in social care with the aim of sustaining the momentum for reform and creating a forum for resolving disagreements. **There must be effective representation of disabled people in our diversity on this group.**
- ❖ Disabled and older people are not a burden! It's time Government started talking about how great it would be to

invest in supporting us to live full lives, about the social and economic benefits of freeing us up to contribute and participate more.

- ❖ Investing in independent living is vital for women's equality and ending human rights abuses against children forced to undertake adult PA roles. The Green Paper does not talk about that.
- ❖ People are suffering now from a disabling social care system. The need for change is urgent, we need to stop faffing about.
 - Once the 'big debate' comes to an end we need ACTION. The Government is talking about a 'White Paper' in 2010 with firmer proposals. But we need legislation urgently – the Independent Living Bill which disabled people wrote with Jack Ashley has all the changes in it we need to see.
 - Government should also take a tougher line with local authorities abusing our human rights now. It's happening on their watch.

3. Make your voice heard and take action

Ok we know you are fed up with consultation after consultation. So are we. But this one is a biggie. The first law of effective campaigning is: get in early, get everyone singing off the same hymn sheet and build alliances with others. We have to use this opportunity to tell Government and debate with friends, family, colleagues the kind of support system we want and need for the future.

So please read the Green Paper and send the Government your views. If you are short of time we suggest you tell them:-

- We strongly agree that there is a need for radical reform.
- Yes we want a nationally funded system.
- We like the vision but you need to pass legislation like the Independent Living Bill to make change like

national assessment, portability and joined up support happen.

- We want a rights-based system that gives us the support we need to get out and participate and live a full life, that's not what we get now.
- Disabled and older people who need it should be entitled to support regardless of 'level' of need.
- Hands off our benefits.
- We want universal, free social care; the Government should develop the Comprehensive model more and work with us on that.
- Disabled people are committed to change; we have huge expertise and we must be involved in taking forward and leading what happens next.
- Government should get a move on: many of us are in urgent need.

This is the link to the care and support website

<http://careandsupport.direct.gov.uk/>

(Department of Health website:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102338

The Green Paper is on there in PDF and Easy Read. Why they don't have a large print version to download we don't know. You have to get other versions from the DH orderline. Hmmm.

You can contact the Green Paper team via email:

careandsupport@dh.gsi.gov.uk

or by post to: Green Paper Team, Room 149, Richmond House, 79 Whitehall, London SW1A 2NS.

The Department are organising lots of meetings about the Green Paper – Mya and Nisha will send you details in case you can go along. Mya and Nisha are also looking at having a Big Independent Living Debate at RADAR's AGM in the autumn.

Meanwhile a new version of the Disabled Persons (Independent Living) Bill will be prepared for the next session of Parliament. Write to your MP and ask them to support it.