



Response to the Green Paper: Shaping the Future of Care Together

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“When we debate the future of adult social care, we are talking about people's human rights and equality, not just for the person requiring the support, but for those with whom they share their lives...[care reform should] deliver a support system where people's human rights are enshrined and everyone's life chances equally valued and supported.”

Baroness Jane Campbell

About NCIL and RADAR

The National Centre for Independent Living (NCIL) and the Royal Association for Disability Rights (RADAR) are user-led organisations established to campaign for equality and justice for disabled people and promote independent living. Central to this is securing a care and support system which supports equal citizenship and the full enjoyment of human rights. Together we directly represent over 500 local disability groups (including Centres for Independent Living (CILs)), and many national disability organisations as well as hundreds of individual disabled people. Through our organisational members we reach several million disabled people.

We believe radical reform of care and support is vital not just for the achievement of equal citizenship for disabled people but for stamping out age discrimination, promoting gender equality, eradicating abuses of children's human rights (when forced to act as carers), promoting equality for carers, strengthening families and local communities and boosting our economy.

How we formed this response

We welcome the national debate on care and support reform and briefed our members at an early stage. Discussion at both our recent AGMs focused on the National Care Service proposals. Our response is also informed by the lengthy consultation with disabled people undertaken as part of the development of Lord Ashley's Independent Living Bill which prefigured many of the Government's current proposals and provides a blueprint for whole-system change. Disabled people were engaged with identifying barriers and designing a new system that would support participation and deliver strong social and economic benefits.

NCIL/RADAR response to the Consultation

What a new National System should look like

Consultation Question

1. 'We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services
- national assessment
- a joined-up service
- information and advice
- personalised care and support
- fair funding.

- a) Is there anything missing from this approach?
b) How should this work?

NCIL/RADAR Response

a) Is there anything missing from this approach?

We believe that independent living opportunities, human rights, quality of life and equal citizenship of disabled people (which includes older people) are undermined by the way adult social care is currently organised and delivered and that the need for reform is urgent.

We support the broad-brush vision for a new National Service and the principles outlined in the Green Paper, although there remains a lot to be clarified. We think it should be called a **National Care and Support Service** to reflect the fact that social care and associated public support services are not – or should not just be – about helping people exist, they should be a springboard to participation as equal citizens and the full enjoyment of human rights including the right to participate in family life, in social and economic activity, leisure, social, cultural and public life.

What is missing: essential elements to incorporate into a new national system, i.e. the National Care & Support Service:

- A commitment to giving people with care and support needs **enough support** so they can actively participate in and contribute to family, social, economic, public and cultural life.
- A clear commitment to entitlement to care and support for people with low or moderate needs. We note the strong commitment in the Green Paper to re-enablement, prevention and early intervention, however we strongly caution against assuming what are (often wrongly) defined as low level needs can be catered for simply by expanding universal services. People with low-vision for example need a cast-iron guarantee of things like low-vision training or mobility training. Free swimming, for example, would not meet those needs!
- A right to early support and treatment for people with mental health issues.
- Specific rights to physiotherapy, speech and language therapy.
- Specific rights to communication support.
- Ensuring individual budgets and direct payments are set at a level which ensures disabled and older people employing their own support workers are able to offer decent wages, pensions, training and decent terms and conditions. This would stimulate markets which would provide services that people want rather than forcing them into what existing services can provide. The subtle intimidation that services have to “close if there are too few who demand them” must stop and give way to true choice and control of those individuals who want new types of support.
- National entitlements alongside national assessment so that people really do have the right to portable care and support.
- A Centre for Independent Living in every local area – it is Government policy that there should be a CIL in every locality by 2010 (although this will clearly not be achieved).
- Specific rights to high quality palliative care and support.

- Freedom to choose your own living arrangements (who you live with, where you live) including the right to be free from the threat of involuntary institutionalisation– as required by the UN Disability Convention.
- Rights to independent advocacy alongside rights to accessible information and advice.
- Measures to avoid the gap between children’s and adults’ services and enable smooth transitions: the Independent Living Bill provides a framework from the cradle to the grave and addresses transition explicitly.
- Clear **enforceable** rights and entitlements

For such a National Service to move from aspiration to reality it will need to be underpinned by a new legislative framework which guarantees enforceable rights to choice and control over public service support and to a level of resources that will enable people to enjoy their human rights in full, participate widely and live the life they want to lead.

This agenda should also involve action on housing. We need a statutory duty for Disability Housing Registers, to mandate the Lifetime Homes Standards for all new housing as quickly as possible, and address barriers to independent living within Local Housing Allowance rules.

b) How this should work

NCIL and RADAR have supported disabled people to engage in developing the blueprint for a new system and the fruits of that are incorporated into the Health and Social Care (Independent Living) Bill which Lord Ashley will reintroduce to the House of Lords on 23rd November. The revised Bill text will be available shortly. Please draw on it for developing the White paper proposals and any subsequent legislative proposals.

This is the way it should work in practice:

- A person who needs care and support (for whatever reason) under the new system should have clear legal rights to independent living support to live the life they want to lead.

- They would know support will be free and that they will be entitled to the same level of support wherever they live. So rather than relying on informal care which puts families under huge pressure, everyone will be free to get on with their lives.
- They should get a single self-directed holistic assessment of all their care and support or independent living needs and be supported to write a support plan setting out what they want to achieve in their lives and what practical support they need to do it.
- They should receive:-
 - clear information about their resource allocation
 - a resource allocation that draws upon all relevant funding streams and which enables them to live with dignity, enjoy real autonomy, keep safe and healthy, meet all their communication, practical support, health and emotional needs, meet their family responsibilities, have a social life, make relationships, enjoy leisure and cultural activities, learn, work and take part in community life.
 - a full range of choices about how to manage these resources with whatever support (from advocates, brokers, Direct Payments Support Services) they need to draw up their own support plan and manage budgets
 - if they opt for cash budget the freedom to spend the resources as they wish (so long as it's legal!) to get the life they want to lead
 - support to engage in collective commissioning with other individual budget holders
- If they needed to move local authority – to take up a new job, to be closer to family or to escape domestic violence - they could do so sure in the knowledge that they would receive absolute continuity of support.
- Everyone would be treated with dignity and respect in all their dealings with statutory services – since staff would have received training in all dimensions of equality and human rights.

If this happened people would be free to participate, the scandal of child carers would be ended, carers would be free to work and build up pensions free from the significant health problems they currently incur, families with disabled children would stop being at 'breaking-point' and start enjoying life.

Local authorities would take the lead in administering this new system which would involve strong partnership duties on other public agencies locally.

National Government would ensure funding streams were integrated and systems in place to deliver this new one-stop empowerment shop.

An existing regulator would be charged with enforcing disabled people's rights in this new system (see the Independent Living Bill).

Delivering the change

Consultation question

2. We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

- a) Do you agree?
- b) What would this look like in practice?
- c) What are the barriers to making this happen?

NCIL/RADAR Response

A) Yes we agree but please see answer to Consultation Question 1, the system needs to aim for much more than this and the gaps need to be filled in.

B) See our response to question 1B for what this should mean for and look like to users of care and support. The Independent Living Bill shows you the legislative framework that is needed to support the new system. It takes a whole systems approach to reform. It shows you what a joined up system rooted in choice and control looks like. It has been designed with the involvement of disabled people themselves and is rooted in knowledge of their lived experiences as well as building on tried and tested systems such as In Control. We would be very happy to come in and go through the Bill with officials and share our detailed Bill Guide with you.

The barriers to whole systems change are primarily legislative and political, but failure to ensure staff are trained effectively and failure to ensure people are

aware of their rights and entitlements and empowered to use them would also impact heavily.

There is no better drive towards joined-up services than that coming from disabled people themselves; choice and control and outcomes set at a national level and agreed in partnership are the means to this end. (NCIL has provided a detailed framework on how an outcomes-based approach could work in the response during the engagement process in 2008). Currently, people are not at all in the driving seat when depending on local authority officers without access to independent arbitration. Quite contrarily to people's needs, it is often local budgetary considerations that dictate what level of support is provided. This is not mitigated but rather reinforced by recent guidance on "prioritising need" and on direct payments.

Personalisation is being rolled out by stealth rather than being supported by strong legislation. That has resulted in widely differing understandings of – and commitment to - 'personalisation' by councils, partner agencies, people who use services and carers, as well as difficulties in extending pilot schemes.

Moreover under current legislation:

- Legally effective self-assessment of care needs is not possible.
- Users of care and support are still referred to as 'cripples' and 'handicapped' - hardly conducive to major culture change.
- Advocacy rights are limited.
- There is no protection against involuntary institutionalisation.
- There are no guiding principles for the delivery of care and support.
- Support for disabled people is highly fragmented resulting in undue hassle and stress in arranging support, unmet support requirements and costly duplication of resources spent on assessment and delivery.
- Self-funders in private care homes continue to be denied the protection of the Human Rights Act.

We could go on. The need for legislative change is urgent.

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 will not work. Joined up services across health and social care would also benefit prevention and reduce enormous costs arising from not meeting needs early on.

Joined up support also demands a coherent set of national entitlements to independent living to replace disjointed entitlements (some very weak) to different services or allowances. The Right to Control provisions in the Welfare Reform Bill will be fraught with difficulty since they seek only to align rather than integrate and do not bring together or strengthen existing entitlements.

Local authorities, NHS bodies and partners on the ground should all be under the same duty to promote independent living and boost outcomes in relation to people's autonomy, health and emotional well-being, participation in work, learning, family life, etc.

The right to control provisions in the Welfare Reform Bill recognise that if you want to give disabled people choice and control you must legislate for it. These provisions need strengthening and implementing sooner rather than later but within a broader new legislative framework that delivers whole-system change.

We strongly emphasise the role CILs and other local disability organisations can play in transformation. In some areas (eg Essex) – user-led organisations are equal partners in the process but this needs to be replicated across the country.

Funding for Care and Support

Consultation question

3. The Government is suggesting three ways in which the National Care Service could be funded in the future:

- Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.
- Insurance – As well as providing a quarter to a third of the cost of people's care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
- Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

NCIL/RADAR Response

a) Which of these options do you prefer, and why?

The lack of further modelling information has made it impossible to make a fully-informed decision. However on the basis of what is set out in the Green Paper **we strongly prefer the Comprehensive System** as it is the only one which:

- holds out the prospect of free care and support for all at the point of use (independent living is after all a human right; and most people assume care and support will be free).
- has the potential to deliver a fair way of funding

The right approach to funding has to be that everyone of us contributes according to our ability to pay, we know exactly what we are contributing towards and what our entitlement is, we mutually insure each other (pooling risk) and then the system is there for us whenever we need it.

As currently outlined the comprehensive system appears to involve both the continued use of general taxation and an additional contribution due when you reach 65, based on ability to pay which you can defer and pay out of your estate. We think contributions would need to be tapered based on ability to pay rather than everyone above a certain threshold paying a fixed sum. This kind of system would need to be extremely progressive and subject to equality impact assessment. Many people just below the set retirement threshold would not have been able to prepare and set aside a considerable amount of money as set. A transition over 25 years to eventually include everyone having to pay into the comprehensive system may also be worth considering. This would reduce individual contributions significantly and reflect the principles of intergenerational solidarity and solidarity between those with different levels of need.

We think the Government should provide more detail and in particular financial models about the Comprehensive system in the White Paper and engage more closely with disabled people in developing this option, about which there remains a good deal of uncertainty and confusion.

We reject the Partnership and Insurance options because:

- they would penalise those with highest needs and lowest means who currently receive free care and support
- most people (wrongly) believe social care is free like NHS Care, therefore these models could face strong resistance
- if insurance is voluntary people will be unlikely to take it up; people tend to prioritise meeting essential needs in the here and now; in any case it is a much better deal to go for the mutual insurance envisaged under the Comprehensive model.

In common with others we think it was **a mistake to rule out funding from general taxation** –an IPSOS/MORI poll for the Disability Rights Commission/EOC/Carers UK in 2006 showed that fifty per cent of respondents backed increased taxes to fund better social care against a quarter of respondents who disagreed. This was also reflected in the feedback that the DH received in their own consultation events. The Green Paper failed to set out all the options. For example, people should have the chance to examine and debate other funding systems such as the **compulsory social insurance scheme** adopted in Germany and elsewhere.

The other things missing from the Green Paper are:

- Acknowledgment of how costly, inefficient and wasteful the current system is and how much this current system costs disabled people and families.
- Acknowledgment of how denying people with low needs timely support or allowing local authorities to make swingeing cuts in care packages and eligibility thresholds impact negatively on the economy and cost tax-payers more (hidden costs).
- Acknowledgement of the benefits of investing in care and support. The more disabled and older people are supported to participate and contribute, the more carers can take up employment opportunities and the lower the cost to the NHS (note: Family and caring responsibilities account for about 26% of inactivity in the UK working age population compared with 19% in Germany and 18% in the Netherlands.)
- Any estimate of the savings that transformation could deliver. Pooled budgets, guaranteeing early support, eliminating multiple assessments and bureaucracy would make huge savings which can then be reinvested or reduce the individual contributions to the Comprehensive system.

Ultimately we seek a comprehensive national system that delivers care and support to all who need it free at the point of use (eliminating charging which represents a tax on disability) and which people feel really is worth investing in. People need to be given a chance to explore what is at stake for themselves, families, friends, communities, etc.

The urgent need for investment

Gordon Brown's announcement at the Labour Party Conference of free home care for those with the most severe needs to care and support from October 2010 is hugely welcome. This is a considerable investment. It shows that when politicians decide something is of vital social and political importance funding can and will be redirected to accomplish it. If Government now accepts it is wrong to charge people with critical needs, what is the rationale for charging those with other levels of need (the costs of which would ultimately be picked up by the taxpayer as a result of a greater burden on the NHS)?

We believe significant investment is required urgently to stem the current crisis and to deliver the aims of care reform. Independent analyses (eg of the King's Fund) have estimated the need for £2-3 billion to deliver services currently required by older people. This does not include services for younger adults. We urge the Government to match its vision with the resources to deliver.

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

No, local authorities should not decide how much funding people receive. National Government should decide. RADAR members voted unanimously for this proposition at the recent AGM.

We welcome the proposed end to the 'postcode lottery' approach (different charging regimes operated by different local authorities). However, this aim seems hardly achievable with local authorities determining as before how much money people get.

If funding decisions remain in the hands of local authorities, there is little prospect for improvement. Leaving fundamental human rights to the discretion of local authorities preoccupied with keeping council tax as low as possible would be a disaster. Access to support would be restricted still further.

We want the White Paper to advocate a fully national system which means:

- 1. Local authorities operate standardised assessments that are set nationally**
- 2. Funding for independent living is provided by the Treasury and ring-fenced for that purpose only**
- 3. A national resource allocation system (with an allowance for regional variations in the cost of support services)**
- 4. Local authorities administering the funding in line with a strong legislative framework delivering enforceable rights and entitlements for everyone with care and support needs to a level of independent living support that delivers real participation.**

Disabled people point out that without a strong national system underpinned by rights-based legislation we will not be empowered to participate in local democracy and decision-making or place-shaping since too many of us will not be able to even get out of our bed or front door, let alone have the time or resources to participate and contribute. The only way to revive localism and ensure we are engaged in running our own communities is to provide us with national, guaranteed rights to and funding for independent living.

We also want caps on local authority spending removed so that they can invest more in public services and we want a system where we work in partnership with local authorities to remove barriers to independent living locally, using a strengthened Equality Duty for example.

Disability Benefits

We welcome the Health Secretary's clarification that there is no proposal to abolish DLA for under 65s. We remain, however, strongly opposed to contemplations of the abolition of DLA for over 65s or AA or any other vital benefits for disabled people to fund English social care. This is because:-

- These extra-cost benefits are not just intended to cover care costs; care needs are the proxy used to assess entitlement not the sole focus of DLA/AA. Disabled people have many extra costs besides care – extra heating and laundry for example.
- Three times as many people qualify for DLA and AA than qualify for adult social care support and the Government is not proposing to extend

eligibility for the latter; therefore removal of these benefits would lead to many disabled people losing out and gaining absolutely nothing in return.

- DLA and AA are not means-tested whereas social care is and again it is not clear what funding system we will end up with and the Government appears to favour one where people only get a small proportion of care free.
- Removal of DLA and AA with no guaranteed cash entitlement to replace it would push many disabled people into poverty.

Over 21,000 people have signed the petition on the PM's website on this issue and we predict these numbers will grow rapidly.

The only circumstance in which we could envisage AA and DLA be replicated in the National Care Service is if Government:

1. commits to passing legislation like the Independent Living Bill which gives disabled people – including those with low-level needs guaranteed rights to free independent living support and the same flexibility (that one has with DLA and AA only) in an individual budget AND
2. creates another way of compensating disabled people for extra costs arising from non-care related issues such as needs for extra heating, extra laundry costs in a way which retains the strengths of DLA and AA (ie no means-testing and freedom to spend the cash as you wish).