



## The Carers Bill

### 10 things to think about...

### A Briefing Paper by the National Carer Organisations

#### 1. Carers want a Carers Bill

*Always, always a duty. If left to guidance it will never happen. (NCO survey)*

Over 450 carers submitted a response to the consultation and over 500 attended a consultation event or responded to our online survey. The overwhelming response from carers was that they support The Carers Bill.

When we asked carers 'Do you think the proposals, if they are implemented, will make a significant difference to carers' lives?' At all of our events 100% of participants answered 'Yes'

A few carers expressed cynicism about whether the legislation will make a real difference to their lives. However, even where these views were expressed the conclusion was still that legislation is the right course of action and has the potential to deliver positive outcomes for carers

*I have real reservations about how this will be interpreted but the need for a **duty** to provide services either directly or indirectly is clear. (NCO survey)*

#### 2. Shifting the Balance of Care – don't shift it on to carers

*There are more demands placed on carers with more people being supported at home (carer, South West Glasgow)*

*There is a need for Carers Legislation to ensure carers are seen as a priority in Scotland (carer, South West Glasgow)*

Current reform to health and social care services, such as self-directed support, reshaping care and integration all embrace the principle of shifting the balance of care to more services being delivered in the home and in local communities.

As the balance of care shifts, carers are likely to play an increasing role both as care providers and also informal care managers. Without their contribution of unpaid care the desired savings from planned reform will not be achievable

Carers must be viewed an essential and finite resource which requires protection and investment, much the same as the health and social care workforce is viewed. The Carers Bill is needed to ensure that the needs of carers are prioritised and that the shifting balance of care does not shift an additional burden onto carers.

### **3. The Carers Bill needs to have a rights based approach**

*Carers Rights should not be seen as a political issue, but a human issue, a community concern, a common responsibility which does and will effect all of us at sometime in our lives. Caring for Carers and securing their rights should never be allowed to be seen as an issue dealt with at 'the discretion' of those in power. Rights are never a privilege, they are the fundamentals which underpin a caring and law-abiding society. (carer, Argyll and Bute)*

Carers are adamant that their priority for the legislation is to deliver tangible rights to recognise and support them in their caring role. Many carers strongly expressed the view that rights were 'overdue' 'deserved' and an important recognition of the money they save society by providing care on an unpaid basis.

### **4. An entitlement to support and short breaks is the number one priority for carers**

*We don't really want that much – some acknowledgment and a little support” (carer, Alloa)*

*The duty to provide short breaks linked to a requirement to produce a statement of short breaks availability at last brings clarity for carers to an otherwise confused situation (COCIS meeting)*

Carers have indicated that the key priority for them is the Duty on Local Authorities to provide them with support according to an eligibility framework. For carers with an intensive caring role this will at long last provide them with a right to services they are assessed as needing. Linked to a duty for local authorities to provide all carers with an outcome focused Carers Support Plan, this will begin to address the failures and inconsistencies in the current system and mean carers will no longer have to 'battle' to get help.

## **5. What's missing? - hospital discharge planning**

*My biggest problems have been at times of hospital discharge' (Carers Rights Charter Survey)*

*Carer support should be a part of hospital discharge planning and it should be available on discharge where appropriate (Carer, North Lanarkshire)*

Despite the existing Scottish Government Protocol on Hospital Discharge, practice across Scotland differs widely and very often, to the detriment of carers. We strongly advocate that hospital discharge must begin at the point of admission with the full and active involvement of carers. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration.

Discharge planning must take account of the level of care that carers are willing and able to provide and should put in place additional support or replacement care where required.

We therefore propose a Duty on health to inform and involve carers in hospital admission and discharge procedures.

## **6. Preventative Support must be a priority**

*Help before you hit the wall (carer, West Lothian)*

The government has made it clear that the intention for carers legislation to strengthen access to preventative support. This is reassuring and we believe the Bill must contain principles around this, backed by strong legislation and guidance. One carer from North Lanarkshire put it well when he said 'if the red warning light in your car goes off – would you just ignore it? – that would be an expensive mistake, so when carers ask for help, don't ignore them.'

## **7. Health needs to play their role in supporting carers**

*Health boards are still slow to understand the needs and role of carers and involve them fully. The duty to provide information keeps them focused on the existence of carers (NCO survey)*

Carers value the role that health has played in identifying, supporting and signposting them, particularly since the introduction of Carer Information Strategies.

With the proposal to repeal Section 12 and the requirement for Health Boards to produce a Carer Information Strategy, there are concerns from carers that health will no longer prioritise carer support. Also that the good practice developed through CIS funding will no longer continue resulting in the loss of valued carer support services.

*When funding runs out, or there is no longer a requirement to produce a NHS Carer Information Strategy, what will happen to these staff and who will pick up the excellent work they do for carers? (carer, North Lanarkshire)*

The legislation needs to ensure that health continues to play its role in supporting carers and that the new integrated partnerships have carer participation and carer support build into their structures from the beginning.

## **8. Building a House on Sand? – developing eligibility criteria**

*Any framework should be produced jointly with carers and be at 'National' level on just local which could lead once again to post code lottery support plans. (NCO Survey)*

*It is important that the eligibility framework is not placed at too high a level meaning many carers would be ineligible for support (NCO survey)*

The biggest single concern about the legislation was the development of the eligibility framework. This will be the foundation on which the new rights for carers will sit. Depending on what it incorporates, it will either improve carers access to support, or create more of a barrier and a greater move towards crisis management.

Carers expressed a great degree of nervousness that the details of the eligibility framework will not be included in the legislation and that eligibility criteria may be developed by individual local authorities. One carer said it felt like they were being asked to 'build a house on sand' since they don't know if the foundation will be there to support them.

We therefore believe the bill needs to contain some principles around eligibility and a commitment to develop a **national** eligibility framework and eligibility criteria in partnership with carers.

## **9. We need to build the capacity of local carer support organisations**

*Carers identify and have confidence in their carers centres. They would not welcome any encroachment by the private sector. (carer, North Lanarkshire)*

Throughout the consultation carers frequently mentioned how much they valued the support provided by their local carer organisation. They also emphasised that the support they most value is **Local** and **Independent**. Many of the proposals are likely to impact on carers organisations, meaning they will be supporting more carers at an earlier stage. They will also be potentially providing an extended range of services, for example, if the local authority devolves its responsibility to undertake Carers Support Plans to them.

Most centres are already operating at full capacity and many have been on standstill budgets for many years. The impact of this legislation on them must be scoped and they must be fully resourced to undertake any additional work.

## **10. The Big Question - How will the Bill be resourced?**

*Definitely need more investment if short break are to be a duty (COCIS meeting)*

*Impact will be that more resources will be required or existing resource will be diluted (a see-saw effect) However, if done in partnership between local authority and health with pooled budgets it will achieve better outcomes for people (carer, West Lothian)*

Many carers we spoke to believed that money could be spent more wisely within the current system and those savings could be re-invested. However they also believed additional resources would be required and that local authorities should invest in carer support with a view to sustaining the caring population.

Supporting carers is not just a moral imperative. There are also compelling financial arguments for protecting carers health by ensuring they have access to support at an early stage of their caring role. To put it simply, the cost of small and inexpensive interventions at the right time is far less costly than providing full time replacement care when a carer becomes ill, or the caring relationship breaks down due to carer strain.

The Princess Royal Trust for Carers (now Carers Trust) calculated that an investment of less than £5million in carer support services resulted in at least £73million worth of social gains in a year.<sup>1</sup> This gain in value arises from carers maintaining better physical and mental health by reducing stress and depression. In addition to this the person who is cared for is more likely to be able to continue living at home, while carers are more likely to be able to remain in employment.

There is no doubt that the Carers Bill will have resource implications. However, carers felt that legislation would lead to a fairer, more equitable system, it would require local authorities to prioritise carer support and start to 'fill in the gaps' that currently exist in provision.

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<sup>1</sup> The Princess Royal Trust for Carers Social Impact Evaluation Report Baker Tilly, March 2011