

Legislation Committee No.5

Consultation on Proposed Carers Strategies (Wales) Measure

Carers Wales and the Wales Carers Alliance Response

Introduction

About Carers Wales and the Wales Carers Alliance

Carers Wales is a campaigning organisation of carers. fighting to improve the lives of all carers. We want people to recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers Wales provides the secretariat for the Wales Carers Alliance, a coalition of national voluntary sector organisations in Wales. The Alliance works together to push for the legislative, policy, resource and service framework that will properly provide support to carers in Wales. The members of the Alliance are detailed at the end of this paper.

For many years, Carers Wales and the Wales Carers Alliance have fought for improved information and advice for carers and for greater engagement by the NHS in informing, supporting and consulting with carers and recognising the role of carers as key partners in the delivery of care. We wholeheartedly support the stated objectives in the proposed measure.

Please note: individual members of the Wales Carers Alliance will be submitting responses to this consultation based on their own organisational perspective. This response is a summary of our collective view.

Comments on the specific questions to be addressed by the Committee

- 1. Is there a need for legislation (by means of an Assembly Measure) to be made to introduce a new requirement on the NHS and Local Authorities in Wales (“the relevant authorities”) to work in partnership to prepare, publish and implement a joint strategy in relation to carers and if so why? If not, what alternatives do you propose?**

Carers Wales and the Wales Carers Alliance believe there is a need for this legislation.

There are several reasons for this:-

- i) Carers still are not getting the information and advice they need in order to cope with roles that are often very demanding and which may change their lives for ever. The lack of the right information at the right time can have long-lasting and

serious consequences for their own well-being, for that of the person they are supporting and for the rest of their family. For example, carers of people with some sorts of severe mental illness and who don't have good information about the condition and possible patterns of behaviour, may be at risk of harm. Other carers, because they don't know how to get help and support, may decide to give up work to care for a family member without being aware of the long term consequences of this decision.

In any one year, a third of all carers are new to caring. In Wales, this is equivalent to about 115,000 people and many more, such as other family members, are indirectly involved. These new carers need to be informed that there are different sources of help and support available for them and the person they support. Otherwise they may struggle on for many years without help and becoming increasingly isolated and marginalised. A study by Carers UK showed that carers with major caring responsibilities were caring for between 3-5 years before they were aware they might be able to get help¹. Most people with long term conditions or medium levels of frailty linked to old age have little or no contact with social services but they do have regular contact with health bodies. The NHS is therefore of key importance in ensuring that these carers get access to the information, advice and support they need to be able to sustain their caring role without having to pay penalties in terms of income, employment, health and social involvement.

- ii) Despite the key role that the NHS should and could play in ensuring carers have access to the right information, there are still major problems. In many parts of the NHS, they do not see supporting and engaging with carers as an important part of their role. Nor do they understand its importance as an effective and sustainable way of improving care for people with long term support needs. For example, there is still limited engagement from health bodies in the development of local carers strategies. Improving the access to and the effectiveness of information and advice to carers is a key component in these strategies. The work on carers strategies is usually led by the local authorities with strong involvement from the voluntary sector and carers. There is engagement from some health partners in some areas. However the level of involvement by health is patchy across Wales and often the representatives involved are not in a position to influence the policies and practice across the whole of their LHB or Trust. It is not yet a strategic priority for the NHS and, without this measure, is unlikely to become so because of other competing demands on resources. This is despite the massive contribution that carers make by the unpaid support they provide to the long term sustainability of the NHS in Wales (equivalent to an estimated £5.69 billion p.a.²) It should be noted that there are health professionals who do support carers and who would welcome this duty and recognise that supporting carers is important in helping the NHS in Wales achieve many of its other strategic objectives. For example, in the widespread consultation events in 2007 on the Carers Strategy Action Plan that Carers Wales organised on behalf of the Welsh Assembly Government, many of the

¹ In the Know – The importance of information for carers – Carers UK 2006

² Valuing carers – calculating the value of unpaid care – Carers UK 2007

health delegates argued strongly for a duty to be put on the NHS to support carers on the basis that if the NHS wasn't required to do something, it was unlikely to be considered a priority.

“ Requirements on the NHS. It was felt that there needed to be a forceful section on the need for the NHS as a whole to inform and support carers, (i.e. primary care, trusts and LHB's). Meaningful QOF and SAFF targets need to be developed to ensure action.”³

2. Are the sections of the proposed Measure appropriate in terms of reforming legislation relating to the provision of information and advice to carers? If not, how does the proposed Measure need to change?

In general, Carers Wales and the Alliance feels the sections of the proposed Measure are appropriate in terms of reforming legislation relating to the provision of information and advice to carers but will make some specific comments on particular issues as outlined below.

In considering this question, consultees *may* wish to consider, in particular, the nature of the provisions in the proposed Measure that:

(a) The definition of appropriate advice and information as defined in the Measure (Section 3);

We support the definition as given. It is sufficiently broad to cover a wide range of situations and this is essential for the strategies to be effective. The information and advice needs of carers are very varied and often complex. Some carers will need detailed and specialist information at regular intervals because of their particular situations and that of the person they look after; others will need only basic information and signposting in the early stages but need to know where to get more expert help if their needs change.

Section 3 (2) – We welcome the power to make further provision as it covers possible major changes of context in the future.

Section 3 (3) – We strongly support this. Carers are contributors to the social and health economies of Wales and should not be charged for services that enable them to continue to contribute.

(b) Local authorities must ensure that in deciding what services to provide to or for a carer or the person cared for, they consult the carer. Also authorities are required to ensure that they consult carers before they make decisions of a more general nature about service provision to or for carers and the persons cared for. (Sections 2 (1) (b) & (c));

We believe this part of the measure has the potential to have an enormous and positive impact on the way carers are engaged with by both health and the other authorities. It will hopefully lead to them being properly recognised and treated as key

³ Carers Wales 2007 – Report from Consultation Seminars on the Re-focussing of the Carers Strategy

partners in the delivery of care to the people cared for. As an organisation that provides advice and information to carers, we are very aware that very often carers are not consulted about care arrangements and actively engaged in the care planning even when they are crucial to the support of the person they look after.

It is still all too common for frail and vulnerable patients to be discharged from hospital without care packages in place and with no consultation with the carer. It should be noted that consultation alone is not sufficient. Carers' needs as well as those of the service user must be taken in to account. Often it is the needs of the service provider which overrides both. A recent and frightening example was of the plan to discharge a patient of 102 back home to the care of his 98 year old wife. She was unwell with a chest infection and had asked that he be kept in until she was more able to cope. The discharge was only delayed after the intervention of a carers' organisation. There are many other examples from other NHS settings where the contribution of the carer is not recognised and their needs to maintain paid work, other family commitments and a life of their own are not taken into account.

We hope this new requirement will be of major benefit to carers and the people they look after.

(c) Welsh Ministers with the power to make regulations about the following:

i. the services in respect of which the duty to prepare a strategy applies;

We agree. The range of services must not be fixed as new key services may develop in the future.

ii. the matters to be dealt with in the strategy;

Agree.

iii. how and when the strategy is to be published;

Agree.

iv. keeping the strategy under review (including setting a period after which the strategy must be reviewed or replaced);

Agree. It is important that regular reviews are built in or the strategies may become redundant.

v. the consultation which must be undertaken before or during the preparation, implementation or review of the strategy;

Agree

vi. arrangements to monitor and evaluate the implementation of the Strategy (Section 5 (2) (a)-(f))

Agree

We believe these powers are essential if the strategies are to be living processes and a priority area of work within the NHS and the partner authorities.

(d) Welsh Ministers would be able, for each strategy, to designate an NHS organisation as the lead authority for the purposes of co-

ordinating and overseeing the preparation and publication of the strategy and any subsequent review.(Section 5 (3));

We believe this is very important and we hope that the normal practice will be to do so. There is a strong risk that if an NHS organisation is not the designated lead authority, the NHS will not see it as an important activity and one which they can opt out of.

- (e) **The proposed Measure would also place a duty upon the lead authority, or, where there is no designated lead, the responsible authorities acting together, to submit the strategy to Welsh Ministers. Welsh Ministers would then be required to inform the responsible authorities that they are satisfied with the draft strategy, or if they were not satisfied, give the responsible authorities such directions as considered necessary for ensuring that the strategy complies with their requirements. (Section 6);**

Agree. This power will be particularly important in the first few years until the process and practice is fully mainstreamed into the day-to-day work of the NHS.

3. How will the proposed Measure change what organisations do currently and what impact will such changes have, if any?

We believe the proposed Measure has the potential to drive a much needed change of policy, practice and culture in the NHS, making many of the services much more focussed on the needs of the patients and carers. The majority of patients with long term care needs get most of their support from a main family carer who, if they are lucky, are backed up with additional support from other family members, friends and neighbours. Health and social care services inevitably only provide a comparatively small part of the care for most people. No matter how essential, specialist, skilled and enormously valued this professional care is, it is only part of the story. The main support tasks for most people in the community are provided by family carers. The proposed Measure will ensure that this major unpaid “workforce” is not left to struggle without access to key information and that their knowledge and expertise is actively sought and used to improve services. The Measure also has the potential to improve the joint working between the NHS, the other responsible authorities, the voluntary and private sectors and carers . The NHS bodies themselves will not be able to provide the range of advice and information that carers need and may not have the widespread experience of effective engagement and consultation that will be needed. However through effective engagement and joint working with key partners in developing the strategies, they will be able to identify and support essential partners who can provide the expertise and knowledge needed to deliver the strategies.

4. What are the potential barriers to implementing the provisions of the proposed Measure (if any) and does the proposed Measure take account of them?

Due to the re-organisation of the NHS, some of the skills, networks and partnerships developed by the former LHB's may be lost, particularly the loss of a designated place for a carer member on each LHB. The loss of co-terminosity of the LHB's and local government areas may also make development and implementation more difficult. The Measure does not specifically take account of these barriers but we do not believe these

particular barriers are insuperable. Other , and perhaps more significant, possible barriers are a lack of real understanding about why supporting and engaging with carers is important to the success of the NHS in Wales, a lack of knowledge about carers and what they need, a lack of time for front-line practitioners to properly engage with carers and a lack of will and commitment

5. What are the financial implications of the proposed Measure for organisations, if any? In answering this question you may wish to consider Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the proposed Measure.

We do not have the expertise to comment meaningfully on the details of the financial implications of the costs outlined. However we believe that, in the medium and longer term, with the demographic changes affecting Wales, the costs of not supporting carers and investing in the sustainability of family support for an increasing elderly population could be devastating.^{4 5}

6. Are there any other comments you wish to make about specific sections of the proposed Measure?

As indicated in our Submission for the LCO, we welcome the fact that child and young people with caring roles are covered by the measure.

Questions 7 and 8

We have no comments on the proposals relating to “subordinate legislation”

Roz Williamson – Director of Carers Wales, Secretary to Wales Carers Alliance

**Wales
Carers Alliance**

⁴ Tipping Point for Care – Time for a new Social Contract – Carers UK 2010

⁵ <http://www.hsmc.bham.ac.uk/news/pdfs/social-care-reform-executive-summary-feb2010.pdf>