

## Re-focusing of the Carers' Strategy for Wales

Consultation Response from Carers Wales

Carers Wales welcomes the opportunity to respond to this important Welsh Assembly document.

We recognise the many benefits that have arisen from the Carers Strategy since 2000 and welcome the commitment to further improvement made in this consultation document. However, we are concerned that the current plans will not achieve the urgent improvements in services and attitudes that carers need.

### Carers Wales

Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers Wales is an organisation of carers fighting to end this injustice and is part of Carers UK.

Our aim is to improve carers' lives.

- We fight for equality for carers. We want carers to have the same right as everyone else to an ordinary life – a fair level of income, access to support to protect their health and well being and access to the world of work, leisure and education
- We seek to empower carers. We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of health and social care services.

Our response to this document is informed by:

- a) A series of consultation events on the strategy with carers groups.. Approximately 200 carers took part in these meetings. Some comments from carers are attached as Appendix 1.
- b) The consultation work we have recently undertaken to develop a Carers Manifesto for the elections in May. We conducted a postal survey of carers across Wales and held meetings (some in conjunction with the strategy meetings above). We gathered information on the main priorities that carers feel is needed to improve their lives. 364 carers responded to the survey.
- c) The strategic priorities of the organisation (2005-8) that were agreed after extensive consultation with carers and other stakeholders in the organisation.
- d) Discussions with the Wales Carers Workers Network.



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## General comments

Carers Wales has been actively involved in the Carers Strategy Review Panel since 2000. We have argued for several years that the Carers Strategy in Wales needs to be re-focused and re-vitalised. This is necessary to reflect the development of two separate sets of demands affecting public policy.

Firstly, there is growing awareness among carers that, despite the political recognition of their role and the legislative rights that have been secured over the past few years, there has not yet been a successful translation from rhetoric to significant improvements in the services and support most carers are likely to receive.

The majority of carers still have to fight long and hard for support. They have grave concerns about the quality, affordability and appropriateness of the services that are available for the people they look after. Too many carers receive no help at all.

Carers need to maintain their own lives as well as provide care. In order to maintain their health, well-being, the demands of their wider family and work, carers need more and better care services for the people they look after and for themselves.

Secondly, there is growing awareness amongst policy makers of the fragility of our health and social care systems. This is an immediate problem and is likely to become more pressing with the projected demographic changes.

There is recognition in this document, and in other recent policy papers, that carers need to be supported if the Welsh Assembly Government is to succeed in creating a better, fairer and healthier Wales. Policy makers recognise the important role that carers play in maintaining the current care systems. If even a small percentage of carers stopped providing care, health and social care will be in danger of collapse. To achieve the policy objectives put forward in the Beecham Review, "Designed for Life" and in "Fulfilled Lives, Supported Communities" requires the continued and increased involvement of carers. This will not be possible without increased support.

Unfortunately, the awareness is largely theoretical. It has not been backed up with the resources that are needed to develop the services that make a real difference to carers ability to continue to care. Wales needs a substantial increase in high quality social care and the effective health care support for people with long needs. The successive carers' grants, however welcome and useful, are insignificant in relation to levels of need. Very major changes in priorities and investment is needed before the government's commitment to carers can be made real for most carers.

The need to meet both sets of demands is pressing. Against this context and against the objectives outlined in the Welsh Assembly Government's own commitment to carers in paragraph 23, the consultation document fails to meet the mark. The re-focused strategy does not set out a clear direction of travel for carers or social care. It lacks ambition and a strong vision. The key actions, while useful in themselves, are not strong enough to drive forward the significant improvements that are needed in the lives of carers or the people they care for.



The lack of additional resources is perhaps the main reason for this. Policy makers in Wales and the UK need to grapple in an urgent, forceful and systematic way with how it will be possible to make the level of investment needed to sustain and develop social care. Until this happens, carers will have no choice but to continue to struggle to meet the needs of their family members and friends with disabilities and long term conditions. Carers rightly want an end to the many injustices they feel exist as a result of fulfilling caring responsibilities without proper support. They see this strategy as inadequate in meeting the challenges they face.

We very much welcome the use of the term, “ key partners ” to describe carers and feel this will be a useful concept with which to engage those many professionals who work with carers but do not understand why carer support is important.

## Specific Comments on the document

The Welsh Assembly Government has asked for comments under the specific headings. Our comments on these are below.

### ***Q1. Are the areas covered by the draft re-focused Wales Carers’ Strategy comprehensive and pertinent?***

The key priority areas outlined in the document are:

- Health and Social Care
- Information
- Support
- Young carers
- Carers and employment

Carers felt these areas are still important but that the actions outlined are not comprehensive or the most pertinent..

### ***Q2. Are any critical issues not covered?***

#### **2.1 Wellbeing.**

The well-being of carers needs to be included within Health and Social Care and needs to cover their physical and mental well-being. Bereavement counselling was cited as a specific issue not covered.

#### **2.2 Equalities and Human Rights.**

The Assembly’s commitment to carers explicitly mentions “disadvantage” arising from caring responsibilities. However, the document does not set the case for supporting carers firmly within the equalities framework or argue for the inclusion of carers as part of the mainstream “equalities” agenda. We believe this is a major omission.

In Northern Ireland, the equality legislation specifically includes people with caring responsibilities as a category protected from discrimination. While this may not be possible in



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Wales in the short term, the advent of the Commission for Equality and Human Rights offers a new opportunity for raising awareness. WAG could require public bodies to include carers in the monitoring of equality schemes.

### **2.3 The Financial impact of caring**

Although carers were aware that benefits and pensions are outside the control of the Assembly, there was concern that the strategy does not clearly recognise the financial impact of caring and needs to look at ways of mitigating the financial disadvantage faced by carers.

**Q3. *Should any part of the draft document be changed?  
If so, how?***

#### **3.1 Format**

The document would be strengthened and made more readable, for both carers and professionals, if the objectives and action plan were set out at the beginning. In particular, the statement of the Assembly's commitment to carers would hopefully make the aim of the strategy clearer. The context and the reflecting back could be annotated and the detail included as explanatory notes at the end.

It would also be useful if there were some case studies to illustrate issues and possible practice points ( particularly around assessments and hospital discharge ).

#### **3.2 Action Plan**

The action points need to include timescales and who is responsible for ensuring action is taken and reporting on outcomes.

#### **3.3 Language**

The terms "Breaks" or "time-off from caring" rather than respite are preferred by many carers.

**Q4. *Are the Key Actions proposed appropriate and relevant?  
Are there other Key Actions that could be included?***

The key actions proposed are generally appropriate but are irrelevant to most carers. The priority for carers is significantly more investment in care services to enable them to have breaks from caring. Therefore they do not see the proposed actions as likely to produce much in the way of direct benefits or immediate help to cope with the huge difficulties that they face day to day and on so many different fronts. Carers want to see much stronger requirements placed on public bodies actively to support carers. Carers want less monitoring and reviewing and more direct action.



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## Health and Social Care

This section needs actions that will ensure health professionals have to become more aware of carers, be involved in assessments and in signposting carers to other organisations for help and support

Some additional action points could be:

- **Primary Care - Health Checks for carers.** A requirement for primary care to undertake regular MOT for carers would mean surgeries would have to have register of carers and the regular contact would enable health issues to be dealt with and provide opportunities to signpost carers to other forms of support. This could perhaps be considered under the Direct Enhanced Services arrangements.
- **Hospital Discharge** – the development of a specific target around carer involvement in discharge plans would hopefully improve practice. Carers thought Hospital Discharge was a very important issue and want WAG to ensure it works better.

## Information

- Information for carers is hugely important but carers do not want to see the very limited resources used for more assessment of the information presently available to carers. There is a huge amount of information available. The problem is how make sure it reaches the carers who need it. Carers want to know that the key professionals they have contact with will at least recognise their role as a carer and signpost them to a source of further help. They feel it is unlikely that WAG is the body best placed to improve information dissemination unless it requires local bodies to co-operate in the production and dissemination of information and agree an information strategy for their area. The local partnerships must include health partners.
- Carers welcomed the commitment to think about training for carers and thought it would be beneficial. Practical skills such lifting and handling and managing medication; capacity building and participation skills were discussed. Carers also mentioned managing stress, dealing with emotions and difficult behaviour.

## Support

- **Carers Assessments.** This is a very important area and warrants a longer, stronger and more directive section. The action points need to be stronger. For example, taking out the qualifier “to seek” in the following action:  
“ *Work with the Social Services Improvement Agency ~~to seek~~ to increase the take-up of carers’ assessments .....* ” would strengthen the statement.



- **Health involvement.** Requirements on health to promote and undertake assessments need to be included.
- **Respite.** This area is one of the most important for carers but the proposed actions are disproportionately weak. If no new resources are currently available for investment in developing new services, there should at least be a commitment to a serious investigation into how this can be achieved over the next ten years. The consultation draft of "Fulfilled Lives, Supportive Communities " also failed to address this issue and this omission weakened the whole document.
- Requiring bodies to include **contingency planning and emergency cover** within care plans for the times when a carer is ill or affected by a crisis is vital.

## Carers and Employment

We welcome the proposed monitoring of the implementation of the Carers (Equal Opportunities) Act 2004 in order to identify and disseminate best practice.

- We would also like to see the promotion and monitoring of the Work and Families Act included in the actions.

We acknowledge the good practice exemplified by the Assembly's own working practices in terms of carer support policies, flexibility and the recent disability equality and gender equality schemes. These measures could be strengthened by:

- The introduction of a carers' equality scheme would evidence the difficulties that carers in the workplace often face as a result of their caring responsibility. The need for flexible working practices should be endorsed as part of the scheme.
- Carers should be included in the Assembly's Combined Impact Assessment.

For external bodies:

- Require public bodies to audit their staff in order to identify employees with caring responsibilities, discuss working arrangements individually or through a (flexible working) forum in order to ensure that the needs arising from the caring responsibility are met and carers do not suffer from stress at work.

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## Appendix 1 – comments from the consultation events

### Comments on lack of new Resources for the Strategy

- General dismay

Some individual comments

*“ Insufficient funding means that only cases of dire emergency can be addressed. The majority everyday care can only deteriorate as inflation reduces the value of the money that is available”*

*“As a current carer, I am very concerned about this”*

*“More money is needed!!”*

*“Regrettable”*

*“This is unfair but not surprising”*

### Comments on services

- On the whole carers experienced helpful and pleasant response at first point of contact with Social Services (usually the Duty Desk).
- There were examples of home carers not respecting the individual’s confidentiality.
- Carers want to meet Social Services staff face to face at the onset of caring.
- Staff attitudes towards carers is patchy, with examples of helpful, supportive and kind workers, whilst others can be patronising.
- Carers would like Social Services staff to listen to them in an effort to understand their needs, even if they are unable to provide a service.
- Carers felt they needed to have their own specific time to talk to Social Services staff and not at the same time as the cared-for person’s assessment.
- Carers want to be treated as individuals and in private.
- Carers would like to know when their contacts in Social Services change jobs and be given a new contact person when this happens.
- Carers find it difficult to get hold of part-time workers, they need another contact when these workers are not on duty.
- Carers want Social Services staff to keep in regular telephone contact, and to do a follow-up visit after the assessment has taken place.
- When carers are in receipt of regular contact and on-going support, they are very appreciative and their sense of value and self-esteem rises dramatically.



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- ❑ The majority of carers are not told they are entitled to an assessment of their own needs and the question arose as to whether staff in Social Services are aware of the Carers Act. Carers want staff to attend training regarding the Act.
- ❑ Carers reported that their views were not reported to senior members of staff and it was left to individual carers to communicate directly with workers in authority, either by letter or telephone.
- ❑ The Social Services 15 working day minimum standard written response to enquiries were not being adhered to.
- ❑ Carers wish their current unmet needs to be recorded in order for Social Services to be able to plan more effectively and respond to their future needs.
- ❑ The re-organisation of local authorities in Wales has been given as a reason why there is sometimes a breakdown in communication and a shortfall in service provision. Carers felt this excuse has now outlived itself.
- ❑ Carers want a copy of Social Services Charging Policy in their area. There was a great deal of anger and shock when carers heard by letter of the increase in charges with no prior warning. Carers were also outraged at the amount of the increases.
- ❑ There is a need for information about emergency cover and out of hours respite care.
- ❑ Although most carers are aware of where and how to request equipment, they are not aware of the type of equipment they require or what is available. Carers want up to date information on equipment.
- ❑ Carers want training and instruction when the equipment is installed. They also report having to wait months for equipment, resulting in injury and damage to their health.
- ❑ Carers reported a reduction in their allocation of respite hours without any clarification of the reasons for the reduction.
- ❑ Who is supposed to be assessed during a financial assessment – the cared for person, the carer, or both? Carers report that in most cases a joint financial assessment is carried out.



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