Response to the Scottish Government consultation on legislation for carers

April 2014

Age Scotland is the leading charity for older people. We believe that everyone should have the opportunity to make the most of later life, whatever their circumstances, wants and needs.

We welcome the opportunity to give evidence to the Scottish Government's consultation on legislation for carers.

> *"Having been a carer myself, I understand the stresses and strains involved in looking after a loved one. There are many, many older carers around the country doing tremendous work looking after their family or friends, but it's often at a cost to the carer's own health and well-being."*
>
> *Dame Judi Dench*

1. Older people and caring

1.1. We welcome the consultation itself and broadly agree with the Scottish Government's proposals. In particular, we agree with the Scottish Government's "case for change" set out in Chapter 1 of the consultation paper.

1.2. In 2010, with our support, our sister charity Age UK conducted a campaign to highlight the needs and experiences of older carers. Their report, *Invisible but Invaluable*,[1] highlighted several principles which we believe should apply to carers of any age:

- The long-term aim must be that carers do not suffer financial hardship because of caring. Financial support for carers should be sufficient to ensure an acceptable quality of life, good mental and physical health, and opportunities for social and financial inclusion. In particular, carers' allowance should continue to be available post-retirement.

- Health providers should encourage carers to register as such with them and consider how they identify carers and offer them support. Health professionals should respect carers' views on treatment options for the person being cared for, in the light of capacity issues and any

[1] *Invisible but Invaluable* (Age UK, 2010). See http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/ID9494%20Invisible%20But%20Invaluable%20Report.pdf

arrangements to deal with those (e.g. consultation and decision-making involving the next-of-kin, welfare guardian and/or continuing attorney).

- Local authorities should have an obligation to inform carers of their rights and the support available to them, and should promote their services and provide information in accessible formats.
- They should be obliged to consider the effects on carers of restrictions on, withdrawal of, or increased charges for social care services in their areas.
- A clear framework should be in place to give older carers greater influence individually and collectively in local authority decision-making, with support offered to enable them to participate.
- A carer moving in with the person they care for so as to allow intensive care in the home should not disadvantage either's security of housing tenure.

1.3. However, as we know and as the Scottish Government acknowledges, the present situation is quite different. The Princess Royal Trust for Carers (now part of the Carers Trust) carried out a survey of older carers in 2011,[2] and found that older carers:

- Typically care more than 60 hours a week and get few or no breaks.
- Struggle to manage finances alongside their caring responsibilities.
- Find that their own mental and physical health suffers from caring, and often neglect their own health by missing or cancelling treatments or operations they need.
- Do not feel able safely and confidently to lift the person they care for.
- Are worried about their future and their continued ability to care, and what will happen to the person they care for if they are no longer able to.

1.4. In addition, the 2010 Age UK report identified that carers themselves are at risk of becoming lonely and more socially isolated. Demanding caring responsibilities make it more difficult for older carers to continue to meet friends and have a social life. There is increasing evidence that loneliness and isolation is hugely detrimental to mental and physical health.

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[2] *Always on Call, Always Concerned* (Princess Royal Trust for Carers, 2011). See www.carers.org/sites/default/files/always_on_call_always_concerned.pdf

2. Response

2.1. Age Scotland supports the joint statement produced by the range of third sector carers' organisations – Carers Scotland, the Carers Trust, the Coalition of Carers in Scotland, Scottish Young Carers Services Alliance, Crossroads Caring Scotland, MECOPP and Shared Care Scotland – and the propositions made in it.

2.2. In this short supplementary response we wish to highlight some of the aspects affecting older carers and what we believe should be done to address these.

2.3. We support the proposal (para 22 of Chapter 2) to clarify in guidance that local authorities can use existing legal provisions to devolve the Carer's Support Plan to third sector organisations. We also support the proposal in the joint statement by carers' organisations that this should further clarify that the legal duties remain incumbent upon the local authority, in particular to follow through on issues identified in the assessment/support plan.

2.4. Identified staff from the authority linking with the third sector organisation carrying out the support planning would be helpful, but we feel is not sufficient alone. There should be a member of staff who is not only identified as a reference point but who has specific responsibility and accountability for ensuring that the support identified in the plan is in fact made available. We believe that policy and guidance should not be predicated on a belief that when a support plan is in place, the carer's needs for support have been or will necessarily be met.

2.5. We support the proposal (para 15 of Chapter 3) to require local authorities to establish and maintain a service to ensure that carers are aware of their rights and the support available. This is subject to the caveat in the joint statement by carers' organisations that this should be clarified so as not to require new services where high-quality, experienced information and advice services for carers already exist, often in the third sector.

2.6. However, there should also be obligations on health professionals and local authority staff to refer people to those services in each local area. Information and advice should be seen as a partner in the design and delivery of care and treatment. For example, carers (subject to appropriate privacy and confidentiality protections) should have greater or even routine access to key information summaries prepared and held by GPs. These are seen as crucially important for emergency care, such as in Accident and Emergency departments in hospitals. Yet carers are most likely to be the people who are first aware of crises arising. Informed carers are far more likely to be able to

assist in ensuring that crises are responded to appropriately. Similarly, carers should know that they have access to health professionals to discuss care and treatment arrangements for the person in receipt of care and to give the benefit of their experience.

2.7. We believe that the support available for older carers in medicines management should be reviewed. Older carers may themselves have sensory or cognitive impairments, and be at risk of confusion in understanding and following complex medicine regimes. It is sadly not uncommon for visitors (and health and social care staff) to discover that older carers have dropped pills on the floor and not realised, meaning that the person being cared for has not taken their medicine appropriately and may have risked negative health consequences. Similarly, some home care workers are allowed to assist by placing medicines in the hands of people needing care but not to help with ensuring that the hand can reach the mouth. In situations where older carers are themselves temporarily unable to help, this situation seems unnecessary and could be improved.

2.8. Older carers often live in fear of what will happen to the person requiring care if the carer themselves dies, becomes incapacitated or otherwise suddenly unable to continue caring (or carrying out all elements of existing care), but are reluctant to admit this to others. Small changes can ensure that these situations are not as life-threatening as they might otherwise be – such as having personal details kept in a box in the fridge for the benefit of paramedics called to a person's home. Health and social care professionals should be strongly encouraged to encourage carers to have these conversations in safe and supportive environments.

2.9. As self-directed support is implemented, we believe that local authorities (and, following integration, health and social care partnerships) should consider how to monitor implementation in respect of the support networks which exist for older carers who are involved in helping the persons they care for make effective choices about their care, and their own capacity to support this. Where carers also exercise continuing powers of attorney, these do not automatically guarantee that outcomes will be better or that processes will be smoother. Carers report that the feeling they have of persistently having to battle with bureaucracy is one of the contributory factors in negative psychological effects.

2.10. Many social care services provided in people's own homes are delivered by private agencies under contract from local authorities. We are concerned that the practice of outsourcing, designed to achieve best value, may mean that local authorities are less able to monitor these services appropriately and hold them accountable on quality and safety grounds. There are reported incidents

of staff of these agencies acting inappropriately or placing older people and their carers in distress or fear. Staff may also have access to key safe codes, for example, and so potentially to the service user's home. The local authority must ensure its staff are aware of their responsibility to reassure service users and carers. In particular, service users and carers should know that there is a process to highlight concerns with a particular social care provider. Authorities should consider how easy it is to find and use these processes and how accessible they are for people who have difficulties communicating or understanding them.

2.11. We appreciate that several of these points, legislation may not be the most appropriate response. However, we believe that the opportunity of this legislation allows them to be aired and considered further. We would be happy to discuss any of the points in this response further. Please contact:

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