

## CONSULTATION ON THE SCOTTISH GOVERNMENT PROPOSALS FOR CARERS LEGISLATION

### CARERS REFERENCE GROUP SUBMISSION

#### 1. THE LAW RELATING TO UNPAID CARERS IN SCOTLAND AND EXISTING CARERS RIGHTS

- 1.1 There has been little change in the legal rights of carers for over a decade. This does not mean that there have not been important changes in the law that impact on carers. Aspects of other statutes and the variety of government guidance that accompanies statutes also affect carers and those for whom they care.
- 1.2 While guidance does not have the force of law, there is nonetheless an expectation that it will be followed and, of course, the failure of a local authority or other body to follow guidance can be a basis for challenging an assessment or a decision.
- 1.3 The rights carers have come from a variety of sources and it is actually quite a complex process to fit it all together in a meaningful way. As things currently stand, the law concerning carers and those for whom they care is not found in one single place. It is found in a number of statutes and it's sometimes hard to understand what the law is actually saying. So there is an opportunity to articulate in a Carers Bill the rights of carers and the responsibilities of public bodies to support them. This will be reinforced by the Carers Rights Charter, which is close to completion and expected to be implemented ahead of the Carers Bill being published.
- 1.4 Some rights carers have are not very specific, often qualified, and not really always entirely clear. For example, a carer may have a right to a carer's assessment, but there is no statutory time-frame for undertaking the assessment once requested. Also, the right to a carer's assessment is conditional on caring duties being "regular and substantial", but there is no clear, universally shared definition of "regular and substantial."
- 1.5 Some existing rights are pretty meaningless. For example, what is the point of a carer's assessment if there is no duty on local authorities to provide the support and resources identified as needed?

#### 2. NATIONAL STRATEGY FOR CARERS AND YOUNG CARERS (2010-2015)

- 2.1 The Scottish Government worked together with a range of partners, including CoSLA, NHS Boards, the national carer organisations and carers in developing both *Caring Together* and *Getting it Right for Young Carers*. This is one strategy comprising of two parts and reflects the different needs of adult carers and young carers, but acknowledges that there are some common issues, particularly around young carers' transition into adulthood.
- 2.2 Two groups support the implementation of the National Carers Strategy:
- Implementation and Monitoring Group
  - Carers Reference Group
- 2.3 The Carers Reference Group supports the Implementation and Monitoring Group and also supports implementation and delivery of *Caring Together*, in respect to some of the action points within the strategy. The group reviews various relevant publications and developments. Members also highlight positive practices, experiences and emerging issues relevant to their respective areas of expertise and representation.

2.4 The Carers Reference Group comprises members from across Scotland who are widely regarded as ‘expert carers’ with strong links to both local and national carer organisations. The current members of the Carers Reference Group are listed in the appendix to this document.

### **3. SUMMARY OF CARERS REFERENCE GROUP POSITION ON PROPOSED LEGISLATIVE MEASURES TO SUPPORT CARERS AND YOUNG CARERS**

3.1 The Carers Reference Group recognises that duties translate to carers’ rights. Taking this into consideration, it supports the inclusion of the following Scottish Government proposals in the Carers Bill:

- A duty on local authorities to support carers according to an eligibility framework and a discretionary power to support carers who do not meet eligibility criteria
- A duty on local authorities to provide and promote short breaks
- A duty on local authorities to offer all carers a carers support plan, including young carers who are about to turn 18
- A duty on local authorities to establish and maintain a service for providing carers with information and advice on their rights, support and access to a carers support plan

3.2 The Carers Reference Group also supports the inclusion of the following additional proposals in the Carers Bill:

- A duty on NHS boards to inform and involve carers in hospital admission and discharge procedures
- The inclusion of emergency planning in carers support plans
- A named person in each health practice, responsible for managing a GP carer register, identifying carers and signposting them to sources of resources and supports to help them in their caring roles

## **4. RESPONSE TO SCOTTISH GOVERNMENT PROPOSALS**

### **4.1 Carer’s assessment/carer’s support plan**

4.1.1 The carer’s assessment should be renamed the carer’s support plan. There is certainly a lot of stigma associated with the term ‘carer’s assessment’. Many carers find the term off-putting and a bit intimidating. It can be misconstrued as judgemental and associated with means testing. Some carers feel that ‘assessment’ suggests that it is their capability to provide care that is being scrutinised rather than their need for support. The term ‘carer’s support plan’ more accurately reflects the purpose, which is to agree the support the carer needs to help them in their caring role, as well as the expected outcome, which is the carer having a life alongside their caring role.

4.1.2 All carers should have access to a carer’s support plan and, in order to improve the uptake, every opportunity should be taken to inform carers of their right to access a carer’s support plan. This should be in the context of an overall health promotion and health and wellbeing strategy. Also, this should not be interpreted as every carer either wanting or needing a

carer's support plan. The "*substantial and regular*" requirement should be removed as there is no shared understanding of what this means. The alternative is to define it in guidance.

- 4.1.3 Both the process of producing the carer's support plan and its content will reflect the level and intensity of the care being provided by the carer. It may be possible to predict the level and intensity of care being provided for condition specific pathways. The process of producing the carer's support plan should also take account of the age and health of the carer. Elderly people can be very private and fiercely independent. Young people may fear bureaucracy in case it leads to family break ups. The process therefore has to be managed with expertise and experience. For some, the carer's support plan will reflect a 'light touch' assessment while for others it will reflect a more intensive assessment. The associated investment of time, energy and resources will vary considerably.
- 4.1.4 Carers and the cared-for person should be able to choose whether the development of a carer's support plan is separate from any assessment of the carer-for person and carers should have access to advocacy should they need it. A carer should have access to a carer's support plan even if the person for whom they care is not in receipt of any social care services. It is important to recognise the potential for conflict of interest when carers' assessments are carried out in conjunction with the assessments of the people for whom they care. Many Black and Minority Ethnic (BME) people who need care expect family members to take care of them and would refuse an assessment of their needs. In such situations, BME carers would miss out on the supports they need if they were not able to access a carer's support plan separate from any assessment of the carer-for person.
- 4.1.5 The overall aim is to increase the uptake of the carer's support plan, especially early on in a carer's experience, so it is important that local authorities and carer organisations are sufficiently resourced to respond. Guidance should make clear that not every carer will either want or need a carer's support plan. However, for those who do, the carer's support plan should be a comprehensive assessment of the carer's needs at that point in time.
- 4.1.6 Unmet need will be identified if all carers are provided with a carer's support plan.
- 4.1.7 Asking any question is a form of assessment and it is important to start the conversation early. The key to these conversations with carers is that they are no longer about simply giving advice. Rather they are about planning and enablement.
- 4.1.8 There should be a duty on local authorities to inform carers of the timescales for agreeing and implementing the carer's support plan. Consideration should be given to extending this duty to the NHS in the context of integrated health and social care services. The carer's support plan should be agreed within six weeks and implemented within 12 weeks of being requested. Carers should also have access to an appeals process when the carer's support plan cannot be agreed. The carer's support plan should be reviewed annually or sooner if the carer's circumstances change significantly. Both Carers and the people for whom they care can go through many changes in the period of a year, so there needs to be a 'change in circumstances' aspect to the carer's support plan.
- 4.1.9 The local authority duty to undertake carer's support plans should remain but with clear guidance on devolving responsibility to the Third sector. There is evidence that the uptake of the carer's assessment has improved in some areas where responsibility for undertaking assessments has been devolved to the Third sector. It does not matter who actually carries out the carer's support plan; it is the quality of the process and the outcomes that matters. However, carers' centres must be sufficiently resourced when accepting responsibility

delegated by local authorities, and the local authority's role should be to resource rather than challenge the carer's support plan.

- 4.1.10 In a situation where the carer lives in a different local authority from the cared-for person, the carer ought to have the right to choose the local authority they see as being the more appropriate to work up the carer's support plan.

## **4.2 Duty to support carers**

- 4.2.1 There should be a duty on local authorities to provide support to carers according to an eligibility framework. This will ensure that, across Scotland, carers most in need of support will receive it and help to protect carers' health and wellbeing. A duty to support must have sufficient resources assigned to it for it to be successfully implemented. There should be a duty on local authorities and NHS boards to ensure sufficient support services are available; otherwise the lack of available services could be used as a reason for not providing the support that carers are assessed as needing.
- 4.2.2 The level of any additional investment needed to fulfil a duty to support carers will still fall far short of the costs that are avoided by having an unpaid carer workforce in the first place. It is recognised that there will still be a particular challenge to providing appropriate supports in remote and rural areas. However, that should not stop us trying to find ways to meet needs.
- 4.2.3 Eligibility criteria must be co-produced with carers and specific to carers. Carers are not service users so existing eligibility criteria for service users across the spectrum of care groups should not be adapted for application with carers. However, eligibility criteria should still reflect the needs of the cared-for person, especially in regard to the physical, psychological and emotional demands these place on the carer.
- 4.2.4 An eligibility framework should also consider carer's health and wellbeing, family and community networks of support and employment status. It is important that eligibility criteria do not set the bar too high; so high that only carers in crisis can access support.
- 4.2.5 Eligibility criteria must be produced at a national rather than local level in order to avoid the inevitable post code lottery across Scotland. A national eligibility framework will allow a carer to relocate to a different local authority area without having to be reassessed.
- 4.2.6 Local authorities should also retain the power to support carers who do not meet eligibility criteria. Preventative support is still very important and there is a fear that resources will be diverted away from this to fund supports for carers who meet eligibility criteria. There is a need for common sense legislation that ensures equality and maintains standards of support.
- 4.2.7 More carers are likely to take up support if they are not made to feel needy. It is important that carers feel valued and are treated as equal partners in care. Carers should not be referred to as users of services, but instead be recognised as recipients of supports and resources required to enable them to carry on caring.
- 4.2.8 A balance needs to be struck between supporting carers in a preventative way and providing direct support at the sharp end of caring. It is important that this is taken into consideration when agreeing an eligibility framework for support to ensure an appropriate distribution of the overall available resource.

### **4.3 Duty to provide and promote short breaks**

- 4.3.1 There should be a duty on local authorities to provide short breaks according to an eligibility framework and to promote short breaks. This will ensure that, across Scotland, carers most in need of short breaks will receive them and help to protect carers' health and wellbeing.
- 4.3.2 A duty to provide short breaks must have sufficient resources assigned to it for it to be successfully implemented. There is no point having the duty, if carers cannot access the kind of break they need when they need it. Local authorities should look critically at investing in social enterprise and community-based short break solutions.
- 4.3.3 A duty to provide short breaks should also cover the provision of respite in crises or impending crises.
- 4.3.4 A duty should be accompanied by a Short Breaks Statement that clearly explains what is available where, how to access available short breaks, and the expected outcomes for all carers and how these will be monitored.
- 4.3.5 Eligibility criteria must be co-produced with carers and specific to carers. Carers are not service users so existing eligibility criteria for service users across the spectrum of care groups should not be adapted for application with carers. However, eligibility criteria should still reflect the needs of the cared-for person, especially in regard to the physical, psychological and emotional demands these have on the carer.
- 4.3.6 Eligibility criteria must be produced at a national rather than local level in order to avoid the inevitable post code lottery across Scotland. A national eligibility framework will allow carers to relocate to a different local authority areas without having to be reassessed.
- 4.3.7 Eligibility criteria should recognise that all carers can benefit from short breaks at any time during their caring role. However, entitlement to a short break should be proportionate to the level and intensity of the care provided.
- 4.3.8 More carers are likely to take up short breaks if they are not made to feel needy. It is important that carers feel valued and are treated as equal partners in care. Carers should not be referred to as users of services, but instead be recognised as recipients of supports and resources required to enable them to carry on caring.
- 4.3.9 The level of any additional investment needed to fulfil a duty to provide short breaks will still fall far short of the costs that are avoided by having an unpaid carer workforce in the first place. It is recognised that there will still be a particular challenge to providing appropriate short breaks in remote and rural areas.
- 4.3.10 Well-timed short breaks reduce the need for people to go into care or be re-admitted to hospital when carers experience crises. This should be of concern to integrated health and social care services. There needs to be some mechanism for shifting some of the costs avoided to fund any shortfall in short breaks provision.

### **4.4 Carers as equal partners**

- 4.4.1 There should also be statutory provision for carer involvement in care planning for service users, subject to the consent, where appropriate, of the cared-for person. At the very least, carers should be involved in care planning that directly involves them. Carers and those for whom they care are the real experts in determining the supports and services they need.

- 4.4.2 There should be statutory provision to the effect that a local authority and each relevant NHS board must collaborate and involve relevant organisations and carers in the development of local carer strategies, which must be kept under review and updated every three years. Statutory bodies should ensure that carers have access to training to enable meaningful participation and that ongoing participation is supported.
- 4.4.3 Consideration should be given to each NHS board appointing an ‘expert’ carer – someone with significant lived carer experience and experience representing carers’ interests - to serve as a non-executive director on the same terms and conditions as other non-executive directors.
- 4.4.4 There should be statutory provision for carer involvement in the planning, shaping and delivery of services for the people for whom they care, and support for carers in areas outside the scope of integration of health and social care. The carer’s ‘voice’ and experience is equally important to the evaluation of these services. Statutory bodies should ensure that carers have access to training to enable meaningful participation and that ongoing participation is supported.
- 4.4.5 The term “*equal partners in care*” needs to be meaningful. Having a seat at the table is important as it enables carers and their representatives to influence decisions that impact on carers and the people for whom they care. However, there is no equality when voting rights are denied (though it is recognised that decisions are generally arrived at by consensus in most strategic, decision-making forums).
- 4.4.6 There should be no doubt that carers value opportunities to be involved in the planning, shaping and delivery of services, either directly or through their representatives. It is often the case that carers continue to attend forums when the attendance of professional members drops off.
- 4.4.7 The resources of carers’ organisations are generally stretched in trying to ensure carer representation on the numerous forums where the carer’s voice needs to be heard e.g. forums for reshaping care for older people, carers’ strategy and health and care partnerships. Carers’ organisations need to be sufficiently resourced to enable them to recruit, develop and support volunteers to take on the role of informed carer representation.

## **4.5 Information and advice**

- 4.5.1 There should be a duty on local authorities to establish and maintain an information service for carers. Existing carer organisations and carers’ centres have long track records of success and reputations for excellent value in providing carers with the right information at the right time at a local level. 90% of carers got their information and support from carers’ centres rather than NHS or Social Services staff and it is stated clearly in the beginning of the consultation document just how good carers’ centres are at maximising the resources they have for the benefit of carers. More importantly they are valued and trusted by carers. Guidance should reflect this. Information services should continue to be part of service level agreements with local carer organisations and carers’ centres rather than being put out to tender or provided through a central website and/or telephone helpline.
- 4.5.2 A duty on local authorities to establish and maintain an information service for carers should cover the provision of information and advice on the carer’s support plan, signposting carers to sources of support, and carers’ rights (Carers Rights Charter). Consideration should be given to extending the duty to the NHS in the context of integrated health and social care.

- 4.5.3 An information service for carers should also cover sources that can help with housing, employment, day care, financial advice, advocacy, legal advice, emotional support, physical wellbeing, fitness and leisure, entertainment, short breaks and holidays.
- 4.5.4 Under section 12 of the Community Care and Health (Scotland) Act 2002 Ministers can require NHS boards to provide local NHS carer information strategies, the key themes of which are carer identification, information and signposting. The funding stream that supports the current requirement to produce local NHS carer information strategies has enabled many best practice initiatives to be implemented in both acute and primary care settings across Scotland. If section 12 is repealed, there needs to be an assurance of the continuance of resources to support established best practice.
- 4.5.5 If section 12 is repealed, the scope of local carer strategies should be widened to include the key themes of the no longer required local NHS carer information strategies, and funding streams should be brought together. This is already happening in some parts of Scotland. Local carer strategies should then be co-produced within the new, integrated health and social care partnerships.

#### **4.6 Stages and transitions**

- 4.6.1 The Children and Young People's Bill should provide the mechanism for managing the transition from children to adult services. The integration of health and social care services should provide the mechanism for managing the transition from adult to older people services.
- 4.6.2 An anticipatory care planning approach should be taken to better manage the different stages of planning. This will entail having discussions with the carer about potential future support needs in different scenarios.
- 4.6.3 In order to improve planning around the different stages of caring, statutory guidance on carer's support plans needs to ensure that maintaining the ambitions of the carer for their life alongside caring is included in the planning. Transitional planning should also take account of anticipated changes in family and community supports that will impact on the carer.
- 4.6.4 The guidance on the carer's support plan should include guidance on managing stages of caring and transitions. Some transitions are predictable, such as the transition from children to adult services and the stages could be managed, for example, as part of an established care pathway. Some transitions are less predictable. Some are the result of unforeseen changes in circumstances. The carer's support plan has to take account of this.
- 4.6.5 Young carers who are likely to become adult carers should also have a carer's support plan and this should be in place early enough to cover the transition from young to adult carer.
- 4.6.6 The carer's support plan should move with a carer who chooses to relocate to another local authority area. The local authority where the cared-for person lives should be responsible for undertaking the carer support plan and for funding the support for the carer, even if the carer lives in a different local authority area, because the local authority would have to support the cared-for person if the carer was not there.
- 4.6.7 There should be an agreed period for the continuation of funding of the carer's support plan by a local authority following the carer relocating to another local authority area. Thereafter,

local authorities can recoup costs from each other; either on a case-by-case basis or on a quarterly or annual basis.

#### **4.7 Young carers**

- 4.7.1 There is a need to legislate to ensure young carers are identified. Every local authority Education department should put in place a young carers Identification plan.
- 4.7.2 Young carers can be involved in the planning and delivery of services, either directly or through their representatives. However, it is important that forums for involving young carers are age appropriate. We need to take meetings to young people rather than bring young people to meetings.
- 4.7.3 A duty on local authorities to provide information and advice to young carers can be delivered through Education services, Young Carer support services and projects, NHS services, and existing carers' organisations and carers' centres.
- 4.7.4 Information and advice for young carers should include their rights and how to access the supports they need, including educational support, employment support, financial support, recreational support and support for their health and wellbeing. It should also cover transitions and how these will be managed.
- 4.7.5 The Carers Bill should cover the sharing of information, where the young person agrees to this, to enable all agencies to work together to help them to achieve their personal life ambitions and goals alongside their caring role. Consideration should also be given to the allocation of a named, long-term support worker for every young carer.

#### **4.8 Planning and delivery**

- 4.8.1 There should be a duty on local authorities to produce local carer strategies. These should be developed in the context of integrated health and social care arrangements, with a requirement to involve carers and carers' organisations in their development with reference to the Carers' Strategy for Scotland.
- 4.8.2 Not all young carers will be accessing children's services and therefore will fall outside the scope of the local Children's Services Plan. Consideration should therefore be given to young carers' strategies being developed alongside carer strategies at a local level. As with the national strategy, this could be one strategy comprising of two parts that reflects the different needs of adult carers and young carers, but acknowledging that there are some common issues, particularly around young carers' transitions into adulthood.
- 4.8.3 Local authorities must ensure there are sufficient services in their areas to meet carers' and young carers' needs.

### **5. ADDITIONAL PROPOSALS FOR LEGISLATIVE MEASURES TO SUPPORT CARERS AND YOUNG CARERS**

#### **5.1 Hospital discharge**

- 5.1.1 There should be a duty on the NHS to inform and involve carers in hospital discharge procedures. In consideration of existing carers' rights, where the care provided by the unpaid carer is included within the hospital discharge plan, the carer should be asked to specify how much care they are willing and able to provide.



## **5.2 Emergency planning**

- 5.2.1 The duty to provide a carer's support plan should cover the inclusion of an emergency plan. This would describe what should happen if for any reason the carer cannot be there to provide care. For example, the carer could be admitted to hospital in an emergency or their car could break down or be involved in a road traffic accident that delays their return.

## **5.3 Carer identification**

- 5.3.1 Carers should be both recognised and identified. Recognition and identification may be closely associated but they are not the same thing. Carers often go unrecognised by services they deal with in their caring role. However, when services recognise that a person is providing unpaid care, the process of identification begins with the carer being advised about their right to a carer's assessment.
- 5.3.2 There should be a duty for GP practices to produce and maintain carer registers. Alternatively, this requirement should be built into GP contracts with the local NHS board. This would ensure accountability and scrutiny of compliance.
- 5.3.3 The GP register should be linked to proactive actions on the part of the GP practice to support the carer, such as annual flu vaccination, annual health checks and extended appointment times.
- 5.3.4 The GP register should also be linked to a carer's support plan and referral to a local carers centre.
- 5.3.5 There should also be a named person within each GP practice to lead on carer support. The named person should be responsible for signposting newly identified carers to their local carers' centre or carers' organisation, so that carers quickly have access to appropriate supports and resources.

14.04.14

## APPENDIX

### CARERS REFERENCE GROUP

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NAME	LOCAL AUTHORITY AREA
Mohammed Afzal	Dundee City
Sue Beer	Shetland Islands
Catherine Bingham	East Ayrshire
Tony Fitzpatrick	North Lanarkshire
Alan Gow	Glasgow City
Helen Harold	Moray
Zarqa Hussain	
Rosemary Kennedy	Glasgow City
Jade Love	
Donald MacLeod	Highland
Claire McDonald	Renfrewshire
Bert Mewhorter	Stirling
Brett Millett	Glasgow City
Catherine Paterson	Argyll and Bute
Eleanor Robertson	
Tom Wightman	City of Edinburgh

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