

Consultation Response: Carers Legislation – Consultation on Proposals

16 April 2014

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 500 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Community Health and Care Partnerships are associate members.

Introduction

The ALLIANCE welcomes the opportunity to respond to the Scottish Government's proposals for carers legislation.

There are 657,000 carers in Scotland, including 16,701 young carers, and it is estimated that the number of carers in Scotland will rise to 1,000,000 by 2037.¹

Carers play a critical role in supporting disabled people and people who live with life – limiting and long term conditions across Scotland to live safely in their own homes and communities, a role often carried out with little support or assistance. As key partners in care, they contribute significantly to society, particularly to health and social care and it is estimated that the cost of replacing the care currently provided by carers would be more than £10 billion each year.²

The ALLIANCE welcomes the development of improved policy and support for unpaid carers and the move towards a human rights based approach. The ALLIANCE co-convenes, jointly with NHS Health Scotland, the SNAP (Scottish National Action Plan for Human Rights) Health and Social Care Action Group and looks forward to working with the Scottish Government and others to progress the commitment to a new 'Carers Rights Charter for Scotland. This will consolidate existing rights, establish a clear set

¹ 'Unpaid Carers', Scottish Parliament Information Centre, 2009,
<http://www.scottish.parliament.uk/Research%20briefings%20and%20fact%20sheets/SB09-08.pdf>

² 'Valuing Carers', Carers UK, 2011,
http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011_Carers_UK.pdf

of principles for the support of carers and emphasise the importance of understanding both the needs of carers and the ways in which central and local government, Health Boards and others can work to ensure that carers are appropriately supported'.

The contribution of unpaid carers will be central to achieving the Scottish Government's 2020 Vision for Health and Social Care³. It is therefore vital that effective and efficient support for carers, preventing future need, is in place to support this shift in the balance of care without a negative impact on carers' health and wellbeing. The proposed legislation is an important opportunity to recognise, and help ensure a consistent and effective level of support for carers across Scotland.

Consultation Questions

The Carer's Assessment: Carer's Support Plan

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

Many carers express concern that the current use of the term "assessment" can be off-putting due to the possible implication that the carer's competence or skills are being judged.

The ALLIANCE therefore supports changing the name of the carer's assessment to the "Carers Support Plan". This term more accurately conveys its purpose, which is to consider what resources the carer needs to support them in their caring role, to maintain and improve their own health and wellbeing and to enable them to have a life outside of caring.⁴

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

The ALLIANCE supports the removal of the 'substantial and regular' eligibility requirement for the Carer's Support Plan.

Importantly, extending eligibility for the Carer's Support Plan to all carers has the potential to provide a route for carers with lower level caring responsibilities to access information and support, and begin planning for future requirements at an earlier stage. As is recognised by the Scottish Government in 'Caring Together: The Carers

³ 'A Route Map to the 2020 Vision for Health and Social Care', Scottish Government, 2013
<http://www.scotland.gov.uk/Resource/0042/00423188.pdf>

⁴ 3.2 'Carer's Assessment : Guidance for National Standards', Scottish Government, 2008,
<http://www.scotland.gov.uk/Resource/Doc/924/0064536.pdf>

Strategy for Scotland 2010 – 2015⁵ preventative, often inexpensive interventions can enable carers to maintain their caring role, delay or prevent the need for crisis interventions and therefore produce cost savings by reducing the need for more acute services at a later stage.

We have concerns, however, that widening eligibility for the Carer's Support Plan could potentially leave the system vulnerable to abuse. It is therefore important that a clear and consistent definition of the term carer is applied which ensures that the contribution that disabled people, people living with life - limiting illnesses and long term conditions make to relationships is not undermined.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

Removing the condition for the cared-for person to be considered as having an assessed need by the local authority does have the potential of extending support to carers providing support in an unpaid capacity. The ALLIANCE supports the removal of any barrier to people with social care requirements to have the support to maintain their independence.

However, the ALLIANCE is cautious that this could prevent the needs of cared – for persons requiring support from being assessed and met. Fully appreciating that the choice of who should provide support is the right of the individual, the option of Self Directed Support should be offered in the first instance.

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Yes - As well as being made aware of their right to request a Carer's Support Plan, it is important that carers are actively encouraged and supported to participate in this process, and provided with a clear understanding of what it will entail, including the potential benefits to them.

The view of the cared-for person is also critical in this regard and as such the ALLIANCE calls for consideration of a third route to the Carer's Support Plan – at the request of the cared-for person.

⁵ 4.5 'Caring Together – The Carers Strategy for Scotland 2010 – 2015', Scottish Government and CoSLA, 2010, <http://www.scotland.gov.uk/Resource/Doc/319441/0102104.pdf>

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

The ALLIANCE supports this proposal for the same reason outlined in our response to Question 1 and welcomes the introduction of a personal outcomes - based approach to the Carers Support Plan.

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

The ALLIANCE welcomes the introduction of a duty on local authorities to inform carers of the time it will take until they receive a Carer's Support Plan. However, completing a carers assessment can be a lengthy and time consuming process and some carers endure long waiting times of many months (in some cases years) for their Carer's Assessment. It is not, at present, clear how this proposal will address this issue.

In our view that the legislation would be strengthened by the inclusion of a reasonable, maximum timescale (e.g. not exceeding 12 weeks) for local authorities to undertake a Carer's Support Plan and to provide the services that carers are subsequently determined to be eligible for, to ensure that carers do not reach crisis situations before receiving support.

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

The ALLIANCE would welcome any improvements in the assessment process which would make it easier for people who are disabled or living with long term conditions and their carers to move from one part of the country to another. However, rather than reviewing the assessment process in isolation, it is important that an approach is taken that addresses the full range of identified barriers⁶ to porting packages of care and support from one local authority area to another and therefore inhibit independent living.

General comments about the Carer's Support Plan

As noted above, the ALLIANCE supports the change of name of the carers assessment to the Carer's Support Plan, however we would like to make a number of

⁶ 'Policy Briefing – Portability of Care and Support', Independent Living in Scotland, 2011, http://www.ilis.co.uk/uploaded_files/ilis_policy_briefing_portability_of_support.doc

general comments about the proposals which are not covered by the questions in the command paper.

Role of the Third Sector

The ALLIANCE welcomes the option to devolve the process for undertaking of the Carer's Support Plan to the third sector. Many third sector organisations have a great deal of experience of working with carers throughout the carers' assessment process and are greatly experienced at supporting its role. Devolving the process for undertaking the Carer's Support Plan could capitalise on this experience and provide benefits for the carer, third sector organisation and the local authority.

However, there needs to be an understanding that the local authority ultimately remains statutorily responsible for the overall performance of the Carer's Support Plan, with a clear process in place for picking up on needs identified as a result of the process. In terms of best practice this should include identified workers from the local authority working closely with the third sector organisation.

Review Process

Given that carers' needs can change dramatically within a short space of time it is important that there is a process for keeping the Carer's Support Plan under review. This should be clearly outlined in any future guidance to local authorities. As a minimum, we believe that the carer should be offered the opportunity for an annual review of their support plan, however they should not be obliged to take this up. In addition, carers should have the ability to trigger a review at any point to take account of a change in their circumstances.

Emergency and Anticipatory Care Planning

The ALLIANCE proposes that the Carer's Support Plan should include a duty to incorporate emergency and anticipatory care planning. As acknowledged within the Scottish Government's Carers Strategy, Caring Together⁷, for the first time there is a generation of people who have learning disabilities who are outliving their parents. As such, there are more lifelong carers of people who have learning disabilities whose caring responsibility will not cease until their death, or until the carer feels that they are no longer able to sustain their caring role.

It is important that carers are supported to consider what arrangements should be put in place should an emergency situation arise that could suddenly leave them unable to care.

⁷ 'Carer's Assessment : Guidance for National Standards', Scottish Government, 2008, <http://www.scotland.gov.uk/Resource/Doc/924/0064536.pdf>

Effective emergency planning has the potential to provide reassurance and peace of mind for the carer, and improve outcomes for the cared-for person by reducing the risk of inappropriate admissions to hospital or care home settings.

Although there are many examples of good practice across Scotland, there is evidence⁸ of significant levels of variation in the consideration given to emergency care planning within carer's assessments across different local authority areas. An opportunity therefore exists to embed consideration of emergency planning within the new Carer's Support Plan process and ensure greater consistency of approach.

Information and Advice

Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

The ALLIANCE supports the proposal to place a duty on local authorities to ensure that information and advice about the Carer's Support Plan and support for carers and young carers is provided.

This is a role which we believe local carers' organisations are well placed to carry out due to their independence and expertise in harnessing the knowledge and lived experience of carers themselves. We have concerns, however, that local authorities may try to establish their own services, rather than resourcing existing carer support services which have already established a local presence. It is important that carers themselves must play a central role in deciding what services are provided in their area, taking existing provision into consideration.

Case Study: Dementia Carer Voices⁹

Dementia Carer Voices, managed by the ALLIANCE, is a project funded by the Scottish Government to 2016 to harness the work of the "Tommy on Tour" campaign and recognise the importance of the carer voice.

The project utilises the personal stories and of people with dementia and their carers to highlight the importance carers being enabled to build and sustain networks of support, preventing crisis situations and feeling enabled to ask for additional help when it is needed.

⁸ 'Picking up the pieces : Supporting Carers with Emergency Planning', ENABLE Scotland, 2012
<http://www.enable.org.uk/campaigns/current-campaigns/Documents/Picking%20Up%20The%20Pieces%20WEB.pdf>

⁹ <http://www.alliance-scotland.org.uk/what-we-do/projects/dementia-carer-voices/>

Another key focus area is empowering people with dementia and their carers to assert their rights as, embedded in the Charter of Rights for People with Dementia and their Carers¹⁰. This includes their right to fully participate in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making.

As part of the project, the ALLIANCE collaborated with NHS Greater Glasgow & Clyde, Glasgow City Council and Alzheimer Scotland in the production of the “It’s Okay To Ask” carer engagement film to highlight the importance of accessing support services available to carers in the city.

Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

Carers Information Strategies have been helpful in supporting the provision of information and advice to carers. If the requirement for Health Boards to produce Carer Information Strategies is to be repealed there still needs to be a continued focus from Health and Social Care Partnerships in identifying, informing and supporting carers, including directing resources to carer support as a continuation of Carer Information Strategy funding. The mechanisms for directing resources to carer support need to be agreed at a national level and embedded within the new Health and Social Care Partnerships.

Support to Carers (other than information and advice)

Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

The ALLIANCE agrees with the National Carer Organisations¹¹ that this duty (if implemented successfully) has the potential to deliver the following benefits for carers;

1. Linking the duty to support carers to clear eligibility criteria would provide greater transparency to carers regarding support they are entitled to and assist them in navigating their way through the system.

¹⁰ <http://www.dementiarights.org/charter-of-rights/>

¹¹ ‘The Case for A Duty to Support Carers and Young Carers’ , The Coalition of Carers in Scotland on behalf of the National Carer Organisations , 2014 , <http://www.carersnet.org/wp-content/uploads/2014/03/Positions-Paper-on-Duty-to-Support1.pdf>

2. By addressing a number of barriers which prevent carers from asking for help in the first place (including uncertainty about eligibility criteria and lack of appropriate provision) carers will be enabled to access early preventative support which can sustain the caring role and prevent crisis situations.
3. The introduction of a duty to support would provide carers with the opportunity challenge decisions made by their local authority in reflecting the national eligibility framework.

In order to achieve these positive outcomes for carers, it is important that the duty to support carers is framed correctly in legislation and supported by strong regulations and guidance.

We propose that the duty to support carers should incorporate the following;

1. A national eligibility framework should be produced to keep geographic variation to a minimum and ensure equity in access to support for carers across Scotland.
2. Eligibility criteria must be co-produced with carers and designed specifically to their needs, rather than being adapted from existing eligibility criteria for other care groups.
3. In addition to the needs of the cared - for person, there are a number of other factors which would need to be considered when developing eligibility criteria. These include the impact of the caring role on a person's health and wellbeing, employment or education status and additional responsibilities outside the caring role.
4. The eligibility framework must take into account the need to provide preventative support to carers to enable them to access the support they need before reaching crisis situations.

"I had a community alarm, and I received 1 hour in the morning care to shower and dress my husband. This was really inadequate but it was all I was offered...My husband was able to be cared for at home only until April 2008 when I was advised it would be better to place him in nursing care as I was really struggling to care for him at home...If I had a better support network I think I could have looked after him myself for longer." **Feedback provided by carer to the ALLIANCE's Dementia Carer Voices Project.**

Question 13: Should we introduce a duty to provide short breaks?

The ALLIANCE welcomes the proposal to introduce a duty on local authorities to provide and promote short breaks. A range of research studies have demonstrated that providing effective short break services for carers delivers both social and economic benefits, by reducing the need for long-term residential care, decreasing demand for health services due to reductions in stress, and improving the health and wellbeing of carers and those they care for¹².

Despite this, it has been reported that the availability of short breaks remains limited and variable across Scotland¹³, with carers facing a number of barriers including a lack of information on available services and clarity regarding access and eligibility.

The introduction of a duty to provide short breaks has the potential to deliver a more consistent and coherent approach to short breaks planning leading to greater transparency, equality of access and accountability. It is also hoped that this will provide an incentive and opportunity to move towards more flexible, person-centred models of respite care, and to explore the potential of community-led initiatives such as volunteer befriending or family placement, where relatively small investments can produce additional capacity.

Stages and Transitions

Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

The ALLIANCE would welcome the introduction of any measures to assist carers in planning for changes and progressions in their caring role over time. However, recognising that every caring situation is unique, it is important to ensure that the Carer's Support Plan is a participatory process which follows a person – centred and outcome – focussed approach.

¹² Research references can be found in, 'Caring Together – The Carers Strategy for Scotland 2010 – 2015', Scottish Government and CoSLA, 2010, <http://www.scotland.gov.uk/Resource/Doc/319441/0102104.pdf>

¹³ 'Raising the Bar – The Case for a Short Breaks Duty', Shared Care Scotland, 2014, <http://www.carersnet.org/wp-content/uploads/2014/03/Raising-the-Bar.pdf>

Carer Involvement

Question 16: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

The ALLIANCE supports the proposal to require integrated and non-integrated bodies to include carers in the planning, shaping and delivery of services for the people they care for and support for themselves.

Carers have a wealth of knowledge and experience and as such are well placed to make a valuable contribution in terms of practical and emotional expertise. It is very important that carers are involved meaningfully in the decision-making processes that affect their caring responsibilities and in the development of health and social care services. It is important, however, that carer involvement is equated to that of the cared-for person to ensure that the principle of an individual's choice and control in shaping their own support and services is maintained.

Integrated Health and Social Care Partnerships will take a variety of forms across the country depending on local circumstances. Some partnerships will include functions outwith the minimum scope of the legislation, for example children's services or housing. A consistency of approach is required to ensure that carers in different areas can expect to be involved – whether functions are integrated within their local area or not. Alongside this, the mechanisms for directing resources to carer support need to be nationally agreed and embedded within the new integrated partnerships.

Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

The ALLIANCE supports the proposal to require integrated and non-integrated bodies to include carers' organisations in the planning, shaping and delivery of services and support for carers.

Carers' organisations, in addition to their role as a provider of support and services are key vehicles through which carers and people who use support and services can be involved and have their voices heard.

Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

The ALLIANCE supports the proposal to enhance legislation on the involvement of carers and young carers in care planning for the person they care for and in shaping support for themselves.

Although the importance of identification, involvement and support of carers as equal partners in care is well recognised¹⁴, evidence identifies a need for further progress to be made in this area. For example, of over 400 carers surveyed about their experiences of being treated as an equal partner in hospital discharge, 45% of carers described this as either poor or very poor¹⁵.

We propose the introduction of a duty on Health Boards to inform and involve carers in hospital discharge procedures. Effective hospital discharge planning should begin at admission stage and involve all parts of the system (family, carers, hospitals, primary and community care services) working together to ensure a quality experience and outcome for patients and carers. Where the care provided by an unpaid carer is included within a hospital discharge plan, they should be able to specify how much care they are willing and able to provide.

Case Study – Stirling Carers Centre

Stirling Carers Centre employs two Carer Support Officers based within the Allied Health Professional team at their local hospital. Working alongside NHS professionals, their role involves identify hidden carers at all stages of their hospital journey and supporting them to navigate their way through the system from admission to discharge. The Carer Support Officers work with carers to enable them to be equal partners in care and therefore play an active role in discharge planning. This ensures that the patients and their carers leave hospital with the appropriate support in place to retain as much independence as possible and minimise the impact and stress of their return home.

¹⁴ 'Caring Together – The Carers Strategy for Scotland 2010 – 2015', Scottish Government and CoSLA, 2010, <http://www.scotland.gov.uk/Resource/Doc/319441/0102104.pdf>

¹⁵ 'Carers Rights Charter Consultation : Summary of selected responses for Carers Parliament 2013' , Carers Scotland & MECOPP, 2013

Planning and Delivery

Question 20: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

The ALLIANCE supports the proposal to introduce statutory provision for local authorities and Health Boards to involve and collaborate with carers and carers' organisations in the development of a local carer's strategy, which it is hoped will embed a more consistent and strategic approach to the development of carers services.

Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Yes – the ALLIANCE believes that the (potential) introduction of a legal duty on local authorities to provide support to carers will be of limited value unless there is a sufficient range of services and providers to meet identified need. Again, it is important that any measures to develop and support the market recognise the presence and expertise of local carers' organisations and resource existing services where possible.

Identification

Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

Under the 2013/14 GMS Contract Agreement in Scotland, GP practices are required to maintain "a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment." Whilst GP practices currently apply a code to an individual's medical record when identifying them as a carer and collectively, this data provides the basis for a carers' register, the contract does not specifically mention a carers' register.

The ALLIANCE therefore believes that carer identification would be supported by the introduction of a legislative requirement for GP practices to maintain a register of carers within their practice.

However, there is limited value in creating a register if it is simply a data collection process. It is important that the identification of carers is linked to supporting actions

such as referral to local carers support organisations, referral for a Carer's Support Plan or triggering a review of the individual carer every six months to identify potential developments in the caring situation and whether additional support is required in terms of the carer's own health and wellbeing. This model could be supported through the use of a named lead individual within each practice to provide a focus on carer identification and support.

Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

The ALLIANCE supports the proposal that Health Boards should be required to report to the Scottish Government on compliance with the core contractual elements of the GP contract. In addition to the number of carers identified, reporting should also include data in relation to the additional actions identified in the response to Question 22.

For more information

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About the ALLIANCE

The ALLIANCE's vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.