Carers (Scotland) Bill

Health and Social Care Alliance Scotland (the ALLIANCE)

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together over 1,000 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

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 co-convenes, jointly with NHS Health Scotland, the SNAP (Scottish National Action Plan for Human Rights) Health and Social Care Action Group. The purpose of the group is to work with partners across health and social care, with public and third sector organisations, to ensure that human rights are more than another box on the checklist of things to consider, but that a human rights based approach is actually used to improve the lives of people who access health and social care.

Do you support the Bill?

The ALLIANCE welcomes the Carers (Scotland) Bill’s aim to enshrine the rights of carers into law. Carers play a critical role in supporting disabled people and people living with long term conditions across Scotland to live independently with support 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 and it is estimated that the cost of replacing the care currently provided by carers would be more than £10 billion each year.

The contribution of unpaid carers is central to supporting the preventative and anticipatory approach to health and social care outlined within the Scottish Government's 2020 Vision. It is therefore vital that effective ongoing support for carers, preventing future need for increased local authority support, is in place to support this shift in the balance of care without a negative impact on carers’ health and wellbeing, or that of the person they care for. The Carers (Scotland) Bill is an important opportunity to ensure the provision of a consistent and effective level of support to carers across Scotland.

1 http://www.scottishhumanrights.com/actionplan
What do you feel would be the benefits of the provisions set out in the Bill?

The ALLIANCE supports changing the name of the carer’s assessment (which can imply that a carer’s competence or skills are being judged) 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 including caring.  

This move, in conjunction with the removal of the ‘substantial and regular’ eligibility requirement for the Carers Support Plan has the potential to increase the number of carers obtaining a Carers Support Plan, through which they can access information and support, and begin planning for future requirements at an earlier stage.

It is important however, that the Bill links clearly with wider programmes of reform and policy developments which impact on the lives of carers in Scotland. In this regard, further clarity is required on the link between the Carers (Scotland) Bill and the Social Care (Self-directed Support) (Scotland) Act 2013, specifically in relation to the potential overlap between the new Carer Support Plan process and the discretionary role of local authorities in providing support to carers through self-directed support.

How do you feel the Bill could be amended or strengthened?

Eligibility criteria

The ALLIANCE welcomes the introduction of a duty to support carers linked to clear eligibility criteria as a means of providing greater transparency to carers regarding the support they are entitled to. We are concerned, however, that the proposed introduction of eligibility criteria defined locally by local authorities will lead to a postcode lottery of support for carers across Scotland. Whilst local best practice and scope for local variation to satisfy varying needs and caring trends are to be fully supported, we do not believe that there is any justification for a variation in the levels of need which trigger an entitlement to carer support.

The introduction of a duty to support carers linked to eligibility criteria is the gateway to new rights for carers. In light of this, these must be clear rights available to all, not at the discretion of local criteria. We therefore support an amendment to the Bill to replace the requirement on local authorities to develop local eligibility criteria with a requirement on local authorities to adhere to national eligibility criteria for carer support, in order to ensure equity of carers rights across Scotland.

The complexity of locally determining eligibility criteria for carer support alongside local eligibility criteria for Self-Directed Support could lead to a

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fractured and unworkable system for families. There may be some circumstances in which a carer is eligible for both carer support and Self-Directed Support. In this situation, clarity is required as to which Act takes priority.

Emergency Planning

It is important that carers and those to whom they provide care are supported to consider what arrangements should be put in place should an emergency situation arise that could suddenly leave them unable to care. The ALLIANCE’s engagement with carers as part of the Dementia Carer Voices project has highlighted that this remains an issue, with carers voicing concerns “Our relationship has changed I do more for him.. I worry for the future what if I get ill?”

Effective emergency planning has the potential to provide reassurance and peace of mind for the carer, and to make sure that the people to whom they provide care have full choice and control over alternative arrangements, thereby reducing the risk of inappropriate admissions to hospital or care home settings.

ENABLE Scotland’s evidence submission to the committee, based on the intelligence gathered from their ‘Picking up the Pieces’ project highlights that although there are many examples of good practice across Scotland, there are significant levels of variation in the consideration given to emergency care planning within the carer’s assessment process across different local authority areas.

Within this context, the omission of emergency planning from the face of the Bill represents a missed opportunity to embed emergency and future planning as a key component of the new Adult Carer Support Plan and Young Carers statement processes.

It is our view that the Bill could therefore be strengthened by the inclusion of a specific provision on emergency planning within Section 8 (Content of adult carer support plan) and Section 13 (Content of young carer statement). We also propose a duty on local authorities to provide information and advice on emergency and future planning within information and advice services for carers (Section 31).

Impact on the third sector

There are a number of provisions within the Bill which will have an impact on the third sector and which will result in additional pressure being placed on third sector resources, particularly on local carer support organisations and

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5Taken from a letter from a carer who has written to Tommy Whitelaw, Project Engagement Lead for Dementia Carer Voices. The project has over 400 letters from carers across the country.
condition specific organisations which provide low level and preventative support to carers.

Section 112 of the financial memorandum\(^7\) accompanying the Bill outlines that £500,000 per annum will be allocated in each of 2017-18, 2018-19 and 2019-2020 to support about 50 third sector providers that support carers in each of the three years at £10,000 each. Many third sector organisations, including many ALLIANCE members, provide invaluable, preventative support to carers across Scotland and are already under resourced to do so. Further clarification is required into how this funding will be allocated and how the Scottish Government and Scottish local authorities intend to support third sector organisations to increase or sustain their capacity to provide this type of support.

The Bill introduces a duty for local authorities to establish and maintain an information and advice service for carers in its area. In light of their independence and expertise in harnessing the knowledge and expertise of carers themselves, we believe that the emphasis should be placed on supporting and resourcing local carer organisations which already have an established local presence to carry out this role rather than local authorities establishing their own services. In this regard, we propose an amendment to Section 31 of the Bill to the effect of ‘the local authority will have a responsibility to maintain an information and advice service for carers and young carers, or establish a service where required.”

In addition, the Bill includes a provision requiring local authorities to involve and consult carers and carers organisations (as well as the relevant health board) in the preparation of local carers strategies. Given their strategic importance, the ALLIANCE believes that the Bill could be strengthened by the addition of third sector organisations (other than carers organisations) to the list of those requiring consultation under Section 28 (4) of the Bill.

Whilst we welcome the requirement to consult carers and carers organisations, carers require support and resources to enable them to participate meaningfully and carer organisations require dedicated resources to deliver this support. To date, the development process for Health and Social Care Partnerships’ integration schemes has not always recognised the capacity of carers and carers organisations to participate meaningfully in the various meetings and working groups required. Further capacity building will need to be undertaken to support carers and the third sector to engage in more effective ways when preparing local carers’ strategies.

**Personal outcomes for carers and young carers**

The aim of the Bill to introduce a personal outcomes - based approach to the Carers Support Plan is to be welcomed, however the current definition of personal outcomes within the Bill is too narrow. Section 4.1 of the Bill states “personal outcomes . . . includes outcomes which would, if achieved, enable

\(^7\) http://www.scottish.parliament.uk/S4_Bills/Carers%20(Scotland)%20Bill/b61s4-introd-en.pdf
carers to provide or continue to provide care for cared-for persons.” Whilst this definition correctly notes that carers have support needs which require to be met to enable them to continue caring, it focuses on carers solely in relation to their caring role, rather than as citizens with aspirations or as relations to those they care for, with emotional associated emotional impacts which need to be recognised.

In the absence of a more complete definition of personal outcomes, there is a risk that consequent support to carers is focused only on sustaining their caring role rather than assisting carers to have a life that includes caring, or enabling them to consider relinquishing the caring role where that is appropriate for them. The ALLIANCE supports an amendment to the definition on the face of the Bill to this effect, and would recommend considering the range of outcomes identified in Talking Points as being important to carers:

- **Quality of life for the carer:** maintaining health and wellbeing; a life of their own; a positive relationship with the person cared for; freedom from financial hardship; able to engage in activities which are meaningful to them, including employment where relevant.

- **Managing the caring role:** choices in caring, including the limits of caring; feeling informed/skilled/equipped; satisfaction in caring; partnership in services

- **Process:** Valued/respected and expertise recognized; having a say in services; flexible and responsive to changing needs; positive relationship with practitioners

These priorities have been consistently reinforced by carers who responded to a survey undertaken by the ALLIANCE’s Dementia Carer Voices project:

“I don’t feel I have much of a quality of life whilst looking after my Dad. Everything I do from shopping to appointments to having a rare night out revolves round my Dad.”

Carers have a wealth of social and economic rights arising from domestic laws and international treaties, as outlined in the Scottish National Action Plan for Human Rights (SNAP). The Action Plan is a practical roadmap for the progressive realisation of the internationally recognised human rights first set down in the Universal Declaration of Human Rights, which includes that every individual is entitled to an adequate standard of living, free from discrimination and has the right to self-determination.

One of SNAP’s key priorities is to create a better culture where people understand their rights and participate more in decisions which affect them.

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In order for this aim to be achieved, it is vital that these human rights are embedded to ensure that people are increasingly aware of what their rights are and what this means for them in practice.

It is therefore important to broaden the definition of personal outcomes to ensure that carers are supported not simply to manage their caring role but to have an independent life including their caring role.

A duty on hospital discharge

An individual’s admission to hospital often results in their relation/partner becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs. Carers have consistently identified that support is not forthcoming. As expressed by a carer who responded to a survey undertaken by the ALLIANCE’s Dementia Carer Voices project:

“Don't make Carers fight for help they get ... It's hard enough without a battle as well!”

Despite discharge processes stating that ‘patients and their carers are involved and supported in the discharge process’ and that ‘the involvement of individuals, carers and family/representatives is an integral and essential part of admission, transfer and discharge management,’ many carers continue to report that their experience of hospital admission and discharge is poor.

Ineffective discharge planning, which fails to fully and actively involve both the cared for person and the carer (to consider additional support or replacement care where required) can result in inappropriate hospital discharges, increasing the likelihood of readmission and placing increased pressure on the carer. For example, Carers UK’s ‘State of Caring’ survey\(^\text{10}\) noted that four in ten of those caring for someone discharged from hospital in the previous year felt that the person they cared for was not ready to come out or that they did not have the right support to be at home.

It is therefore important that carers are fully involved throughout the process from the point of admission to ensure that carers are able to participate in decisions which affect them (this must be done with the consent of the person to whom they provide care) and that they are recognised by health and social care professionals as equal partners.

A key focus for SNAP is to increase organisations’ ability to put human rights into practice. In pursuance of this aim, it is essential for organisations to be proactively incorporating the principles of participation in their processes and procedures, as well as culture. Discharge planning must therefore be done in partnership with the person and their carer, allowing a meaningful opportunity to plan for discharge and to consider additional support or replacement care where required.

\(^{10}\) http://www.carersuk.org/for-professionals/policy/policy-library/task=download&file=policy_file&id=212
Equalities statement

Scotland is a diverse nation and as such the Carers Bill should reflect this. The number of BME carers has more than doubled in the last decade\textsuperscript{11}, and the ALLIANCE joins the National Carers Organisations in calling for an Equal Opportunities Statement to be included on the face of the Bill.

The Scotland Act (1998) allows for Parliament to legislate within parameters to ‘encourage’ equality of opportunity, through ‘the encouragement (other than by prohibition or regulation) of equal opportunities and in particular the observance of the equal opportunities requirements’ and ‘the imposition of duties on Scottish public authorities, and cross-border public authorities in relation to their Scottish functions.’

The ALLIANCE suggests that the Carers (Scotland) Bill utilises this mechanism supported by robust monitoring and recording processes, as per SNAP’s priority action 3; namely increasing accountability through human rights based laws, governance and monitoring. Local authorities and health boards should be required to develop a statement setting out how they will encourage equality of opportunity for those with protected characteristics to access and benefit from carer support services. Equalities data should be collected and submitted annually to the Scottish Government for monitoring against the statement and publication. Evidence of the process followed in delivering against the Statement should also be included. The Scotland Act powers have already been utilised within the Regulation of Care (Scotland) Act 2001 and the Mental Health (Care and Treatment) (Scotland) Act 2003 amongst others.

The ALLIANCE supports the third sector statement on the Bill coordinated by the National Carers Organisations, which can be downloaded at www.alliance-scotland.org.uk/download/library/lib_552f9edaa596c.

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About the ALLIANCE

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.

\textsuperscript{11} 2011 Census
About Dementia Carer Voices

Dementia Carer Voices works to:

- Capture the experiences of carers across Scotland with a view to informing future policy and service provision
- Raise awareness of the issues around caring for someone with dementia including among health and social care professionals, students and the wider public
- Highlight the role of carers as natural resources; carers as people with needs; carers as people with independent lives
- Empower carers by providing information based on the Charter of Rights and Carers Strategy about caring for someone with dementia
- Harness the awareness raising activity undertaken by Tommy Whitelaw.