Carers (Scotland) Bill

Carers Scotland

Carers Scotland is a charity led by carers, for Scotland’s 759,000 carers - our mission is to make life better for carers. Amongst other activities, we give expert advice, information and support through our dedicated advice line for carers and campaign together for lasting change.

Carers Scotland welcomes the opportunity to respond to the proposals for a Carers Bill. We welcome the Bill and are pleased that the Scottish Government has decided to introduce legislation aimed at delivering new rights and much needed support to carers.

Carers Scotland, as part of the national carer organisations, has submitted a detailed response to the Bill. This full response is also available on our website at www.carerscotland.org. This response mirrors this submission and provides a summary of the proposals which we support and areas which we feel could be strengthened or added to improve the Bill.

1. Adult Carer Support Plan
We have, with carers, campaigned for many years for carers to have a right to recognition and support. We therefore welcome the proposals to offer all carers an Adult Carer Support Plan (ACSP), rather than simply those who met the regular and substantial threshold. We believe this, along with other proposals to remove restrictions to the ACSP, is welcome and will open up access to much needed information, advice and support to carers.

We believe that the introduction of ACSPs is a welcome development. They can be crucial tool in reaching carers at an earlier stage in their caring journey and in preventing crisis. However, organisations that support carers may experience greater demand for their services if more carers being identified. It is important that additional resourcing and support is available to services.

Currently carers can wait for many months or years to receive a carer’s assessment. A defined timescale for an adult carer support plan or young carer statement, set out in a local carers’ strategy, is positive, but the timescales must be reasonable. We believe a defined reasonable timescale must be stated in regulations to ensure parity between local authorities and to make sure that carers have at least some idea of how long it will take to receive a plan

Applications for support for people at the end of their lives and their carers should be dealt with as quickly as possible. Marie Curie is calling for automatic eligibility for carer support for those people caring for someone who has a terminal illness as indicated on a person’s Key Information Summary (KIS), an information sharing system for advanced care planning, or upon receipt of a DS1500 form, which enables someone who is terminally ill to claim Disability Living Allowance or Attendance Allowance from the DWP. We fully support the call from Marie Curie for a commitment of no more than seven days to prepare an ACSP for carers of those with a terminal illness.
2. **Young Carers Statement**
The Young Carers Statement (YCS) is generally welcome but there are some concerns. Firstly, the added value of the young carer statement as distinct from an adult carer support plan is not clear in the Bill or accompanying documents. Young carers do need specific support in their caring role, and this must be distinct from a Child’s Plan as not all young carers will want or need a Child’s Plan. However, the YCS appears to be identical to the adult carer support plan and it is not clear how tangible the young carers statement will be.

3. **Information and Advice**
Carers Scotland welcomes a duty on local authorities to provide information and advice to carers, we maintain this is best achieved by resourcing existing services that work with carers, and only establishing a new service if there is an identified gap. Despite assurances that local authorities will not seek to establish a service in areas where carers’ services already operate, the text of the Bill is ambiguous. We believe it would be possible to amend the legislation to recognise existing service provision and to ensure that local authorities do not establish a service where one already exists.

4. **Support, Eligibility and Prevention**
Carers Scotland welcomes the proposals to introduce a duty to support carers, linked to eligibility criteria. However, in line with our response as one of the national carer organisations, we believe that such eligibility criteria should be national rather than locally developed. Carers, no matter where they live, should be able to access the same level of support where there is a similar level of impact and intensity of caring role.

It is the trigger of the level of service that would be decided by eligibility criteria and not the type of service the carer choose the access. This does not mean that we do not support the concept of local best practice and the scope for local variation to meet varying needs and caring trends. Services which are suitable for carers in Glasgow may not be suitable for carers living in remote communities where transport and accessibility are a greater concern.

The Bill includes the provision for local authorities to have a power to support carers who do not meet eligibility criteria (where local authorities will have a duty to support). This is vital in delivering preventative support to assist carers in supporting their own health and wellbeing. However, we have concerns about what may be specified as general support under the Bill and thus available freely to all carers, whether or not they have an Adult Carer Support Plan, and what is “bespoke” and only available following an ACSP.

Whilst carers should be encouraged to develop an Adult Carer Support Plan, and support services should aim to ensure that carers are able to access an ACSP should they wish to, there should be recognition that timescale for provision of an ACSP are not set and, as such, it make take some time for a carer to be able to access services and support. Universal, freely accessible services are vital to ensure that carers are able to sustain their caring role, health and wellbeing in the interim. Furthermore, carers may not wish an ACSP at that time but instead may require small interventions such as peer
support to sustain their caring role. Carers also may take time to identify themselves as carers. Self referral (or referral by another agency e.g. GP) to a carers support service may be their first step. It is vital that the process for accessing support in the first instance should not be overly burdensome.

Carers Scotland believes that the Bill should specify that all carers should be eligible to free access to a range of universal services including, for example, information and advice (which is already specified in the Bill), emotional and peer support and general carer support. The Bill should specify that local authorities should have a duty to ensure that a baseline level of universal, freely available services are provided for carers in their area.

5. Waiving Charges
In addition, we note that the financial memorandum (paras 88-98) discusses the issue of waiving charges for support and services to carers and that, which it is “fully expected” that regulations to waive charges will accompany the Carers Bill will be produced. The current regulations prevent carers being charged for support they receive in their own right, which is identified in a Carers Assessment. This position, particularly the principle that carers are equal partners and service providers and as such should not be charged for support, must not be lost.

6. Personal Outcomes
Carers Scotland believes that the definition of personal outcomes within 4(1) is narrow and, in effect, relates to inputs rather than outcomes. These are defined in Measuring personal outcomes: Challenges and strategies as “all the resources a group needs to carry out its activities.” We agree that identifying the needs (i.e. resources) a carer has for support and services to continue to care safely is vital and is an integral element of the Bill (recognised in 5 2)).

However, whilst we welcome the inclusion of personal outcomes and the recognition that carers have needs for support to enable them to continue caring, we believe 4(1) should be amended to better define personal outcomes that to recognise carers not solely for their caring role but as citizens with aspirations.

Caring is a normal part of life but should not mean individuals face significant negative impacts on their finances, ability to work and take part in learning, health and wellbeing, social and leisure opportunities. Without defining personal outcomes more fully we risk support to carers being focused solely on sustaining their caring role.

Such an amendment should be included on the face of the Bill and further defined in regulation. It may be helpful to, for example, refer to Talking

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1 This list is not exhaustive

2 Measuring personal outcomes: Challenges and strategies, IRISS Insights, no.12 (January 2012)

3 Also referred to in policy memorandum “Wider Initiatives” para 15
Points\textsuperscript{4}, which is highlighted in the policy memorandum supporting the Bill but not translated into the definitions of personal outcomes within the Bill itself.

7. Short Breaks
We believe it is unfortunate that the government has decided not to take this opportunity to introduce an additional specific duty around short breaks. In our view, the general Support Duty, as it stands, does not tackle directly the need for local authorities to actively plan to improve the availability, choice and flexibility of short break provision. At the very least we would propose that a further addition is made to Section 28 on the preparation of local carer strategies to include specifically local authority plans for developing short breaks provision, taking account of current provision, an assessment of unmet need, and the demand for different types of break.

The aim should be to deliver short breaks that better meet people’s needs, that families and people who use services are happier with those services, and consequently that short breaks will be more effective and achieve better outcomes.

With reference to the duty to ‘consider’ whether support should take the form of a break from caring, we are concerned how this might be interpreted.

We would prefer that those eligible for support, with have an identified need for a break(s), should be offered a quantified, minimum level of short breaks, which would be clearly stated in their Support Plan or Young Carers Statement, and which would be made available through the different self-directed support options. The government has already stated that adult and young carers should not be charged for the support they receive - including any charges related to enabling breaks from caring - and we would expect this position to continue.

We also welcome the introduction of Short Breaks Statements. However, we would expect a statement to go further than just a list of the “different types and the range of short breaks that might be available”.

It must include significantly more detail, for example the range of local short break supports; eligibility criteria; details of universally available, accessible recreation and leisure opportunities. This will ensure greater transparency around how short breaks are accessed and allow comparisons between the different approaches to provision across the country, which may help drive up standards.

8. Impact on Third Sector
There are many provisions within the Bill that will have a direct impact on the third sector and will result in additional pressure being placed on third sector resources, particularly on local carer support organisations and condition specific organisations who support carers. We are concerned that the impact on carers’ centres and the wider third sector has not been fully recognised within the Bill.

\textsuperscript{4} Also referred to in policy memorandum “Key Definitions” para 60 - Talking Points: Personal Outcomes, Practical Guide, Ailsa Cook and Emma Miller, Joint Improvement Team (2012)
The additional duties on local authorities to provide carers with information and advice and to support carers who meet eligibility criteria will inevitably result in an increase in the number of carers identified and a corresponding increase in demand for services. Previously hidden carers will begin to seek early and preventative support and as the majority of these carers will not meet eligibility criteria, it is likely that they will need to access universal support services provided by the third sector. Resourcing for the third sector to improve their capacity will be required in order for carers to be identified and supported.

Carers will require support and resources to enable them to participate meaningfully and carer organisations require dedicated resources to deliver this support. The development process for Health and Social Care Partnerships’ integration schemes has not always recognised the capacity of carers and carers’ organisations; 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.

9. Carers Strategies
It is positive that local authorities will have a duty to prepare and publish a Short Breaks Statement and that Local Authorities must develop and publish local carer strategies, to involve carers in the development of review of strategies and to review these every 3 years. We believe that this will bring greater transparency to carers in each area and may assist local authorities in learning from experiences and developments in other areas.

10. Involvement
We welcome the duty placed on Local Authorities and Health Boards to involve adult carers, young carers, carer organisations and other relevant organisations in the planning, shaping, delivery and review of services. It is positive that this duty will extend beyond the provisions within the Public Bodies (Joint Working) Act where this is already required.

Involvement of carers and taking account of their views in determining the needs of the person being assessed and deciding what services to provide and how to provide them is important. Carers have unique experience and knowledge of the person they care for and local authorities should draw on this knowledge. We therefore welcome the duty being place on local authorities to involve (with consent) and take account of views.

However, it is vital that in such assessments that there is a clear link between the delivery of the individual’s personal outcomes and what support the carer is willing and able to provide. We therefore welcome that Local Authorities will be required to take into account the care provided by an unpaid carer when conducting an assessment of the cared-for person. Where there is an Adult Carer Support Plan in place they must take account of this and where there is not they must still take account of the care provided and ascertain that this is what the carer is ‘able and willing’ to provide. However, we believe that there must be clear guidance to practitioners and those who make decisions on funding of care packages to ensure that carers are not, however inadvertently, expected to provide care at a level they are not able or willing to do.
11. Wider Policy

We welcome the recognition that the Carers (Scotland) Bill cannot sit in isolation but must sit with and link with a wider programme of reform and policy development. This should include strategy and policy linked not only to health and social care but also to other wider social issues such as employment, social security and pensions and the reduction of poverty and inequality. We welcome the recognition in paragraph 15 of the policy memorandum that wider initiatives may “need some adjustment and tailoring to take into account the responsibilities of caring.”

As part of the Bill, there should be a requirement to consider the impact on carers of all policy across Government be considered.

It is also important to recognise the wider context within which the Bill sits. In particular, the significant challenges faced in delivering social care services within reduced financial circumstances at both national and local government level. Whilst we recognise these pressures, many carers face reducing care packages for the person they care for, support that is not delivered until crisis occurs, increasing charges for care that is provided and families supplementing the costs of care and adaptations where packages do not meet the full set of needs. This is not intended to be negative but simply to recognise the context within which the Carers (Scotland) Bill will be developed and implemented. The financial memorandum outlines a range of new funding to support the delivery of the Bill, which we welcome. However it is vital that these funds are protected to ensure that they do not simply replace existing social care budgets and deliver effective early support for carers, preventing crisis and enabling carers to have a life outside caring.

In addition to the suggestions for amendments and improvements above, Carers Scotland believes that the following should be included within the Carers Bill.

12. Additional Developments

(a) Provisions to recognise and involve carers are welcomed. However, they stop short of recognising carers as equal partners in care. Carers have clearly stated that they believe the Carers Bill needs to include a statement recognising carers as equal partners in care.

(b) We support proposals and concerns by Enable Scotland about the lack of emergency planning provision on the face of the Bill and believe the Bill would benefit significantly from the inclusion of a specific provision on emergency planning within ACSP and YCS. We would also propose a duty on local authorities to provide information and advice on emergency and future planning within information and advice services for carers. We are clear that emergency and future planning is a health and wellbeing issue for carers and the individuals they care for. The omission of emergency and future planning from primary statute is a missed opportunity to have a profound and positive impact on outcomes for carers and the people they care for.

(c) In taking forward the very positive developments in the Carers Bill, we
believe that it could be furthered strengthened by the inclusion of an Equal Opportunities Clause and support the submission made by MECOPP. The Scotland Act (1998) allows for Parliament to legislate within parameters (as equality is a reserved matter) to ‘encourage’ equality of opportunity. In supporting MECOPP’s position, we would recommend that the Carers bill utilises this mechanism supported by robust monitoring and reporting processes. 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.

(d) We have made specific reference to the role of health services on hospital admission and discharge below, however, the support of carers by health services links to the much wider policy agenda mentioned earlier in reducing health inequalities and improving health. General practice also has a vital role to play. In the original Scottish Government consultation on legislation reference was made to extending and consolidating the role of general practice in identifying and referring carers to support. However, the Bill does not bring specific provisions and the policy memorandum (para 122) notes that it “would be difficult to have a law about identifying people who are carers”. It also recognises that the identification of carers is “hugely important as it is a prerequisite to assessment and support.”

Identification of carers remains a challenge despite a wide range of initiatives designed to improve this. GPs are in a unique position to be able to identify carers who may be attending the practice to support the person they look after as well as attending for their own health needs, and therefore GPs and allied health professionals are perhaps the best placed people to identify carers at any stage in the caring journey. However, identification of carers through GP practices remains inconsistent across Scotland and there is limited evidence to suggest that GPs actively seek to identify carers they come into contact with.

Carers Scotland believes there should be a legislative requirement for GP practices to develop a register of carers within their practice. The coding mechanism is already in place to enable a register to be created, but there is limited value in creating a register if it is simply data collection. In addition to the identification of carers, GPs should be required to proactively refer carers for an Adult Carer Support Plan, which should also be recorded on the individual patient record.

The carers’ register should trigger an offer of an appointment for the individual carer every six months to determine if the caring situation has changed and whether additional support is required in terms of the carer’s own health and wellbeing including an annual health check. There is currently some good practice in the provision of health checks for carers and carers are included in the Keep Well initiative but these should be implemented more widely and consistently. A legislative requirement to identify carers would assist and a method of measurement would also be required to ensure such activity is moving in a positive direction.
(e) There is a range of policies and protocols in place to make the process of hospital admission and discharge run smoothly. These aim to ensure that patients receive the timely care in the right place and have safe discharge from hospital to a more appropriate setting. Despite these 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.

The Scottish Government did not include this in its earlier proposals and it has not been included in the Carers Bill. Despite the existing Scottish Government protocol on hospital discharge, practice across Scotland differs widely and very often is to the detriment of carers. It appears that much of carers’ experience of hospital discharge has not improved greatly since the publication of “You Can Take Him Home Now” in 2001. At that time, nearly three quarters of respondents were not given any choice over whether or not they provided care. Although two thirds had been consulted about hospital discharge plans, 43% felt that those arranging discharge did not take their concerns, ideas and comments into account. One in three people had to go back into hospital within 2 months of being discharged, with a third of carers saying this was due to them being discharged too early.

Carers Scotland therefore recommends that a duty is included in the Carers Bill to require health boards, and other relevant partners, to inform and involve carers fully in hospital admission and discharge procedures. This includes effective support where the carer has been a patient and requires appropriate recovery and recuperation time.

(f) Carers report difficulties with obtaining redress through the social work complaints system. The social work complaint system is often difficult to navigate and carers have little redress outwith the local authority. They can only complain to the Scottish Public Services Ombudsman if there is maladministration or service failure on the part of the local authority. Beyond this carers could apply for judicial review but this can place a cost and risk to carers finances. The Scottish Government response to this report recommended that the SPSO expanded its remit to take on a similar role to that of the Complaint Review Committees. This would provide the SPSO with a remit over social work decisions in line with its role in relation to NHS complaints.

We are aware that the Working Group was set up to consider this recommendation. However, we unclear of progress and when we may expect these recommendations to be implemented. We are aware that there are also considerations of how best to deliver a high quality complaints system within new integrated services.
The Bill itself will deliver new rights for carers but it is vital that, should carers not obtain these rights, that a method of redress that is both easily accessible and delivers outcomes is in place.

Conclusion
Carers Scotland welcomes the Carers Bill. The Bill has many new developments which we believe with effective implementation and resourcing can make a positive difference to carers lives. However, there are a number of areas where the Bill could be strengthened and improved which would offer greater support, recognition and redress for carers, enabling them to sustain their role as equal partners in care.

Carers Scotland
About Carers Scotland

Across Scotland today, more than 759,000 people are carers, supporting a loved one who is older, disabled or seriously ill.

That’s 1 in 8 adults who care, unpaid, for family and friends. Three in five of us will become carers at some point in our lives and, within our lifetime, there will be 1 million carers in Scotland.

Every day 500 people in Scotland become carers. Many don’t know how or where to get help. It can be frightening and very lonely.

Caring is such an important part of life. It’s simply part of being human. Carers are holding families together, enabling loved ones to get the most out of life, making an enormous contribution to society and saving the Scottish economy £10.3 billion each year.

Yet many are stretched to the limit – juggling care with work and family life, or even struggling with poor health themselves – and finding it difficult to make ends meet.

**Carers Scotland** is a charity led by carers, for carers – our mission is to make life better for carers.

- **We give expert advice**, information and support
- **We connect carers** so no-one has to care alone
- **We campaign** together for lasting change
- **We innovate** to find new ways to reach and support carers.