Carers (Scotland) Bill

Carers Trust Scotland

1.1 We welcome the opportunity to provide evidence to the Health and Sport Committee on the Carers (Scotland) Bill. Since the Bill was introduced we have consulted with carers and our network of partner organisations by participating in focus groups and events where carers and carer support organisations can provide information and views on the Bill and how they feel it will affect them. This submission summarises and reflects these views as much as possible.

1.2 Carers and carers’ organisations mostly welcome the Bill. They are pleased that the Scottish Government is committed to introducing new rights and entitlements to unpaid carers. However, some aspects of the Bill require strengthening and there are also several things that we feel could be added to the Bill. Key areas that require strengthening include the lack of clarity around short breaks, the distinct role and responsibility of health boards in delivering change, particularly in relation to carer support at hospital discharge, and the omission of emergency and future care planning on the face of the Bill.

Benefits of the provisions set out in the Bill

2.1 The provisions in the Bill that establish adult carer support plans are welcomed by carers. Carers will be identified earlier in their caring journey, enabling them to access support at an earlier stage which may help prevent crisis. However, an increase in the number of carers identified and seeking early and preventative support will have a further impact on organisations that support carers.

2.2 Provisions that widen access to adult carer support plans are also welcomed, particularly the removal of references to a carer’s ‘ability’ to provide care. Referencing a carer being ‘able and willing’ to provide care provides more options to manage a caring role alongside a life outside of caring – this is also supported through a personal outcomes approach, and there are some changes that could be made to Section 4 of the Bill to ensure that carers’ personal outcomes outside of a caring role are properly defined. This is further explored in paragraph 3.1.

2.3 We welcome the commitment that guidance will be issued on adult carer support plans, which will include information on different stages of caring and the need to review the carer support plan at periods of transition such as discharge from hospital or changes in the carer’s personal circumstances. It is also positive to see clarification that when the carer and cared for person live in a different local authority, the area in which the carer resides should prepare the carer support plan and provide or meet the costs of any support to be provided, as carers will be able to use this clarification in cases of dispute.

2.4 A duty to support carers based on eligibility criteria and a power to support carers in a preventative manner when they do not meet eligibility criteria is
welcomed by carers and carers’ centres. However, there are also concerns about local eligibility criteria which are discussed in detail in paragraph 3.13.

2.5 It is positive to place a duty on local authorities to develop and publish local carer strategies and to involve carers and carers’ organisations in the development of these. It should hopefully lead to greater transparency for carers to see how their local area plans to identify and support carers. Further duties to involve adult carers and young carers, carers’ organisations and other relevant organisations in the planning, shaping, delivery and review of services, and for involving carers in determining the needs of the person they support and deciding what services to provide are also welcomed. However there are some concerns about capacity of carers and carers’ organisations to participate meaningfully, and about confidentiality and consent issues when carers are involved in decisions about the care and support of the person they look after. These are discussed in paragraph 3.4 and 4.6.

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

3.1 The Bill defines personal outcomes for carers related to their caring role. We believe there should be recognition that carers are entitled to a life outside of caring, rather than just a life alongside caring. The definition of personal outcomes within Part 1 Section 4 of the Bill is very narrow and relates to inputs rather than outcomes. 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, we believe the Bill should be amended to better define personal outcomes that recognise carers not solely for their caring role but as citizens with aspirations.\(^1\) Caring is a normal part of life but should not mean significant negative impacts on a person’s 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 the caring role.

3.2 An amendment to address this oversight in personal outcome definitions should be included on the face of the Bill and further defined in regulation. Talking Points\(^2\) is highlighted in the policy memorandum supporting the Bill but not translated into the definitions of personal outcomes within the Bill itself. Talking Points identifies a range of outcomes that are important to carers, such as

- a life of their own
- being valued/respected and having their expertise recognised
- satisfaction in caring
- freedom from financial hardship

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\(^1\) Also referred to in policy memorandum “Wider Initiatives” para 15
\(^2\) Also referred to in policy memorandum “Key Definitions” para 60 - Talking Points: Personal Outcomes, Practical Guide, Alisa Cook and Emma Miller, Joint Improvement Team (2012)
Outcomes such as these will help to protect carers from any negative impact on their lives from caring.

3.3 The provisions in the Bill that establish adult carer support plans are welcomed by carers. However, organisations that support carers may experience greater demand for their services if there are more carers being identified. It is important that additional resourcing and support is available to services that provide preventative support as they will see an increase in demand. Changes to the assessment process will have a particular impact on carers’ centres who complete carers’ assessments on behalf of the local authority – this currently happens in several areas – and best practice indicates that consistency and clear ‘reporting lines’ from both organisations are key to successful outcomes for the process and also for carers. Whilst Section 8 (1) of the Bill is clear about what information the ACSP must contain, if eligibility criteria is set locally then there is still potential for variation in the contents of the ACSP, which will lead to a ‘postcode lottery’ of carer support and carers’ experiences of the ACSP.

3.4 Whilst we are pleased that local authorities will be required to take into account the views of the carer when determining the needs of the person being assessed for care and support, some carers have raised the issue of confidentiality. Caring relationships can be complex and these complexities must be recognised in guidance and regulations accompanying the Bill.

3.5 The Young Carers Statement is generally welcomed 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 needs to be distinct from a Child’s Plan as not all young carers will want or need a Child’s Plan. However, the Young Carers Statement appears to be identical to the adult carer support plan. There are also concerns about the wording within the Bill of ‘appropriate’ caring roles undertaken by young carers. Services for young carers operate on the basis that young carers are children first and foremost, and should not take on caring roles that affect their wellbeing, development, or the ability to have a life outside of caring. In the list of content of the young carer statement, there should be greater distinction that young carers ultimately have a choice to not provide care.

3.6 It is noted in the Policy Memorandum that there may be confidentiality concerns about the content of the YCS being available to the young person’s named person. Sometimes young carers do not want information about their caring situation shared with their school (even if this would lead to additional support for them). Consideration should be given to information sharing between services to ensure that the privacy of the young carer is respected, and that information is not shared without the consent of the young carer. Information will have to be shared about the young carer in the development of a statement, and due care should be given to respect the young carer’s
right to confidentiality and to ensure that information sharing is relevant and proportionate, and considers the best interests of the young carer. It could be that the content of the young carer statement would only be shared with the named person if it is essential to their wellbeing based on GIRFEC principles.

3.7 Currently carers can wait for many years or months 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 and we believe a defined reasonable timescale must be stated in regulations to ensure parity between local authorities. The timescales should reflect both the time for local authorities to undertake an assessment and also to provide the services that carers are eligible for, to ensure that carers do not reach crisis point before they receive support. The predicted increase in carers seeking early and preventative support means that reasonable timescales are vital to ensuring carers receive support when they need it, and not when they are reaching crisis.

3.8 In addition to this, we support the call by Marie Curie for mechanisms on the face of the Bill that allow automatic qualification for carer support for people caring for someone with a terminal illness, and for a quick completion of an adult carer support plan for carers of those with a terminal illness. Caring for someone at the end of life can be physically and emotionally demanding and is often characterised by uncertain and unpredictable condition trajectories. These carers often need unique and responsive support; however many are not identified by health or social care services, or self-identify formally as carers. They often do not know about or access the support they need, and financial support is often received late in a person’s illness, or even after the person’s death.

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. Marie Curie also call for a commitment of no more than seven days to prepare an adult carer support plan for carers of those with a terminal illness; we fully support this.

3.9Whilst we welcome 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. Many third sector organisations provide information and advice to carers and their families. These range from carers’ centres and carer support services – organisations that provide services to all carers or specific groups of carers – to condition-specific organisations, general advice
services like Citizens Advice Bureaux, and specific advice services such as debt advice, housing advice or energy advice. Carers’ services have often been established in a local area for many years and are well used, with many services operating at capacity; almost three quarters of services were clear that they would not be able to cope with extra demand at their current level of resourcing.

“We are currently at capacity with the numbers coming through the door increasing every year. Staff are stretched to the maximum at the moment. If the numbers continue to increase then waiting lists will result. At the present... we operate an appointment system and Adult Carer Support is booked up and cannot offer an appointment [until] approx. 2 weeks later.”

These services receive core funding from local authorities; there are concerns that a duty on local authorities to provide information and advice will lead to resources being diverted away from carers’ services in order to provide services in-house instead. Carers really value a dedicated, independent carers’ service and are concerned that the Bill may encourage local authorities to establish a service that provides information and advice but does not go above and beyond this in the way that dedicated services do.

3.10 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 and we believe that Part 6, Section 31 should be altered to reflect the contribution of independent carers’ services, to ensure that local authorities do not establish a service where one is not needed. Independent carers’ centres and carers’ services can already provide expert information and advice on all the services outlined in the Bill and in many cases, will also provide the service. This reduces signposting and is more convenient and supportive for the carer. In most situations, it will be better to support an existing service that has a well-known presence in an area, that carers already know and trust and that is skilled at identifying hidden carers and those who are new to caring.

3.11 In addition, these dedicated services offer a much wider range of services than information and advice. They provide vital support for carers who are struggling, an opportunity to receive direct support from professionals and peers, an opportunity to relax and have a break from caring, and other services that complement the information and advice that they receive. This kind of holistic service is unique to carers’ centres, and services providing information and advice only would not replace this.

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3 Carers’ services finance enquiry, Carers Trust Scotland and Coalition of Carers in Scotland, November 2014.
4 There are carers’ centres in 30 local authorities. The Shetland Islands and the Western Isles have some online and telephone-based carer support services but no carers’ centre.
3.12 We are concerned about the lack of emergency planning provision on the face of the Bill. It is our view that the Bill would benefit significantly from the inclusion of a specific provision on emergency planning within Section 8 and Section 13, and 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 (Section 31). Emergency and future planning is a health and wellbeing issue for carers and the individuals they care for, and consider the omission of emergency and future planning from primary statute as a missed opportunity to have a profound and positive impact on outcomes for carers and the people they care for. ENABLE Scotland are funded by The Scottish Government to deliver their ‘Picking up the Pieces’ project which is analysing the impact of emergency planning, focussing on carer health and wellbeing and the reduced pressure on services. This is guiding their evidence submissions throughout the Bill process. We fully support ENABLE Scotland’s position on emergency and future planning within the Carers (Scotland) Bill and direct the Committee to their evidence submission in this respect.

3.13 There are significant concerns about the Bill’s provision for a duty on local authorities to provide support to carers who meet local eligibility criteria. The Bill will only be viewed as successful if it delivers real change in the form of a right to support and resources to assist carers in their caring role. Eligibility criteria is the key to them unlocking their right to support. We therefore cannot stress enough how important it is to get this criteria right, because as well as delivering an entitlement to carers it also has the potential to tighten eligibility, undermine a preventative approach and make it harder for carers to access support. Inevitably some local authorities will develop stricter criteria than others, meaning some carers will be at a disadvantage. It will also mean there will be less transparency, as it will be very challenging to compare service provision across local authorities and carers will be unlikely to have an understanding of what they are entitled to. England and Wales have recently introduced national eligibility criteria for care services and there are many examples of European countries which developed national eligibility criteria for social care, including carer support.

We fully support scope for local variation to meet varying needs. Services which are suitable for carers in cities may not be suitable for carers living in remote and island communities where transport and accessibility are a greater concern. However, there is no justification for a variation in the levels of need which trigger an entitlement to support, and therefore no justification for not defining national standards of eligibility so that carers are able to access the same level of support when they have a similar level of impact and intensity of caring role. It is the trigger and level of service that would be decided by eligibility criteria, not the type of service the carer chooses to access.

3.14 The Bill includes the provision for local authorities to have a power to support carers who do not meet eligibility criteria, as well as a duty to support those who do. We are pleased that this is recognised as essential in ensuring
a preventative approach is taken to supporting carers and protecting their health and wellbeing. The Bill describes the duty to provide support to carers as applying ‘where a carer has identified needs which cannot be met by services or assistance provided generally to persons in the area of the responsible local authority’ (Section 22 (1)). Much of the support that carers access locally is provided by carer support organisations. This support does not require them to have a statutory carer’s assessment, is universally available and is preventative, helping to sustain their caring role.

3.15 The Bill does not define which services are general. However, in the policy memorandum it describes eligible services as ‘bespoke services’ and states ‘Bespoke support would include, for example, short breaks, training, advocacy and emotional support’ (Page 22 (92)). Currently many of the services which are described as ‘bespoke’ in the policy memorandum are available to carers as general or universal support, without the requirement to meet eligibility criteria. For example, many carers benefit from training to assist them in their caring role. This may be training on moving and handling to ensure they avoid injury, or courses explaining the condition of the person they care for and how it can be self-managed. Carers may also access emotional support in the form of peer support or counselling, advocacy or support to have a voice and be recognised as an equal partner in care. In most cases this is provided by the third sector through local carer organisations and condition specific organisations. This enables early identification of carers and prevents carers from reaching crisis. To put this in context, only a small percentage of carers access statutory support following a carer’s assessment, with the majority accessing support through universal services.

3.16 With an increase in the number of Adult Carer Support Plans being undertaken there will be a corresponding increase on the demands on universal services. It is essential that these supports continue, are properly resourced and that they are not defined too narrowly. The Bill should specify that all carers should be eligible to free access to a range of universal services as well as information and advice (which is already specified), emotional and peer support and general carer support and should also 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.

Is there anything that you would add to the Bill?

4.1 The Bill should make provision for a duty to be placed on health boards to involve carers in hospital discharge planning procedures for the person they are looking after. An admission to hospital often results in a person 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. Despite stating that ‘patients and their carers are involved

5 This list is not exhaustive
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.

4.2 To create sustained and consistent improvement, which we believe would benefit both carers and those they care for, hospital discharge planning must begin at the point of admission with the full and active involvement of carers. Discharge planning must take account of the level of care that carers are willing and able to provide (if at all) and should put in place additional support or replacement care where required. The policy memorandum recognises that hospital discharge is a point at which an adult carer support plan might require review, which indicates recognition that discharge is a process which can be stressful for the carer and the person they are looking after. The provisions in Section 27 to take carers’ views into account when determining services to provide for the cared for person, would also be strengthened by introducing provisions around hospital discharge planning.

4.3 In addition to including a duty on health boards to inform and involve carers in hospital admission and discharge procedures, we believe the role of health needs to be further strengthened within the Bill. There have been many positive outcomes arising from Carer Information Strategy funding, including early identification of carers, the signposting of carers to support organisations and an increased awareness of the needs of carers amongst health professionals, with nearly £28m of funding allocated since 2008. In addition, funding has been awarded to carer support organisations to employ specialised staff like hospital discharge liaison workers, dementia support workers and older carer support workers. It is important to continue to build on this best practice and to strengthen the Carers Bill in relation to the ongoing role of health in identifying carers and providing them with appropriate information, signposting and support.

4.4 In line with Shared Care Scotland, we are disappointed the government has decided not to take this opportunity to introduce a specific duty around short breaks. The general duty to support does not tackle directly the need for local authorities to actively plan to improve the availability, choice and flexibility of short break provision. With reference to the duty to ‘consider’ whether support should take the form of a break from caring, it is not clear how this might be interpreted. We would prefer that those eligible for support should be given a quantified, minimum entitlement to short breaks, which would be recorded in their Support Plan or Young Carers Statement, and which would be made available through the different self-directed support options. Eligibility criteria and how these relate to the levels of short break support available should also be clearly explained in the Short Breaks Statement.

4.5 We are concerned that the impact on carers’ centres and the wider third sector has not been fully recognised within the Bill. 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 access universal support services provided by the third
sector. The assertion in the financial memorandum that the Bill will not lead to
direct costs for the third sector seems flawed; third sector services are already
facing significant pressures due to changes to funding the impact of welfare
reform (amongst other issues) and the wider policy context in which they
operate. Although the need for additional resources is recognised in the Bill, it
will require more than transformational costs for systems and processes. Resourcing for the third sector to improve their capacity will be required in
order for carers to be identified and supported.

4.6 The Bill’s requirement for local authorities to involve and consult carers
and carers’ services in the preparation of local carers’ strategies will also
impact on the third sector. Whilst we welcome this focus on carer involvement,
carers require support and resources to enable them to participate
meaningfully and carer organisations require dedicated resources to deliver
this support. 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.

Carers Trust Scotland