Introduction

Headway – the brain injury association is delighted to have been given the opportunity to share its views on the Carers (Scotland) Bill. We are a UK-wide charity providing support to brain injury survivors and their families and carers through a variety of frontline central services complementing the work of a network of local Headway groups and branches, who provide a range of services in their communities. We additionally raise awareness of brain injury, and seek to prevent further injuries through our communications, policy, research and campaigning work.

At present, there are nine Headway groups operating in Scotland, each providing a range of services to brain injury survivors and their families and carers. For survivors, they offer a variety of rehabilitative activities to promote cognitive, behavioural, physical and emotional recovery, which can include hydrotherapy, cooking and other independent living skills, individual therapy, and exercise sessions. These additionally offer social opportunities for survivors which can rebuild their confidence. Scotland also has five Headway volunteer-led branches which provide a range of social inclusion programmes and give information and peer support through volunteers.

Additionally, many Headway groups and branches in Scotland offer support to carers, which can include befriending and dedicated carer events where carers can socialise, find information and access peer support. There is also information on caring for a brain injury survivor on Headway’s website and a specially created booklet for carers, and it takes a large number of calls on its helpline from this group. The charity has also previously campaigned on support for carers, and offers training to them in caring for someone with a brain injury. Courses cover issues including cognitive rehabilitation, communication difficulties, and sex and sexuality.

1. **Do you support the Bill?**

1.1. Broadly, Headway is very supportive of the Bill. It represents a significant step forward for carers in recognising their contribution to the community and in providing them with a statutory basis through which they can look to access support from Local Authorities.

1.2. Headway is acutely aware of the invaluable support that carers provide. For brain injury survivors, carers can assist them in both their rehabilitation and day to day care, and through doing so they represent great savings to the public purse.

1.3. Brain injury can impact on a person’s cognitive, behavioural, physical and emotional skills and abilities, and so a brain injury survivor may need a

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1 This can be found at [https://www.headway.org.uk/caring.aspx](https://www.headway.org.uk/caring.aspx).
wide variety of care; from eating and bathing, to supporting them to communicate, and assisting their mobility and independence. Whilst many carers will actively choose to provide this assistance because of their love and compassion for the individual, it can be stressful and physically and emotionally draining if they themselves do not have adequate support.

1.4. Consequently, we encourage and support measures, such as this Bill, which will better enable carers to continue in their caring role as long as they wish and are able, and in a way which is both supportive and respectful of their contribution to the community. This said, we have some comments and suggestions on the Bill’s content to share, and which we call on the Committee to explore and progress during its examination of the Bill and its representations on it.

2. What do you feel would be the benefits of the provisions set out in the Bill?

2.1. Headway believes the Bill could provide a number of benefits to carers in Scotland. Placing a statutory duty on Local Authorities to support those who meet their eligibility criteria is a step forwards in recognising the support carers need and the considerable contribution they make to community and the life of the person being cared for.

2.2. We are pleased that the Bill, as it stands, will enable all carers to be assessed for support. We hope that this will result in support for a greater number of carers through Adult Carer Support Plans. We believe this is important, as maintaining the wellbeing of carers supports them to continue providing a care role as long as they are able and wish to. In turn, this is also indirectly supportive of the person being cared for as it increases consistency in their care. For brain injury survivors this is particularly important, as change can have a negative impact on their wellbeing.

2.3. Headway welcomes the duty included in the Bill to ensure that local authorities develop, publish and regularly review a local carers strategy, and ask that they are fully supported to do this with the appropriate guidance and resource. This positive and proactive step would enable Local Authorities to build up a strong base of knowledge as to carers in their area and their levels of need, along with what services exist and where there are any gaps. We additionally welcome the transparency here in the Bill stating that these would be published; this will allow relevant people and organisations to have insight into the Local Authority’s plans, and to provide feedback if necessary.

2.4. We are additionally pleased that the Bill refers to the carer being ‘able and willing’ to provide care, rather than simply able. This acknowledges that whilst a carer may be able to provide a certain level of care, they may not be willing for them to do so. Caring requires an individual to be emotionally, physically and mentally able to assist the person needing care, and some may not have all three of these abilities at all times. Some may also have other important considerations, such as maintaining a particular work pattern or providing care to other dependents when deciding how much of a caring role they can take on.
2.5. A person’s financial situation can also be a significant factor here. Caring can be a full time role and Headway is aware of situations where carers have needed to leave their paid work to take on this responsibility. This can add financial pressure to an already emotionally challenging situation, and in turn can create stress in the relationship between the carer and the person they care for. As such, some carers will take the decision to remain in employment so that the family has a better quality of life.

2.6. Taking these factors into account, we are pleased that the Bill takes a more rounded view of a carer’s ability to take on caring responsibilities. It shares the caring role between the carer and the Local Authority, should the carer decide against, or be unable, to provide their maximum level of care. We feel this is particularly important in the case of those who provide care to brain injury survivors, where the demands on the carer can be great and may require a great deal of their time and energy – both physical and emotional.

2.7. Headway also welcomes how the Bill seeks to provide local authorities with the power, for reasons of prevention, to support carers who do not meet the eligibility criteria. We believe this proactive approach is important as it would enable local authorities to invest in situations ahead of problems arising. This would better support the carer, whilst also potentially saving Local Authority resources that would have been needed in the future should problems have occurred.

2.8. We are pleased the Bill promotes beneficiary involvement. This is very positive; it is important to enable carers to participate in processes which are designed to help them, and to take their feedback as this increases the chances of the resulting plans and services being tailored to effectively meet their needs.

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

3.1. There are several elements of the Bill that Headway believes should be altered or amended to ensure that carers are able to access support which is consistent, appropriate and avoids duplication.

3.2. Local eligibility criteria

3.2.1. Headway is disappointed that the Bill places a duty on local authorities to develop their own local eligibility criteria, as stated in Pt3, s19, rather than establishing a national criteria. We are very concerned that would lead to a lack of consistency in provisions for carers across Scotland, as local authorities may set their eligibility thresholds at very different levels. We feel this would be unfair, and believe that access to support must be equitable across the country. Furthermore, creating national criteria should be more cost effective than each Local Authority working on its own variation.

3.2.2. We call on the Committee to raise this important issue in its review of the Bill. Headway believes this is a critical issue within it, and that it must be considered to ensure that disparity does not undermine the positive intentions. With Headway services across Scotland often serving more than one Local
Authority area, it will be plainly clear if there are disparities in the support offered to carers linked to these. This may prove distressing for any of those who may receive less support whilst in similar circumstances to others, and may in turn put greater pressures on local voluntary services to fill support gaps.

3.3. Including carers in developing local carer strategies

3.3.1. As mentioned above, Headway is delighted that the Bill includes provisions to encourage carer involvement in developing Adult Carer Support Plans, in carer services and local carer strategies. However, we feel that this should be strengthened in the case of the latter.

3.3.2. At present, Pt5 s23 (4), states that ‘Before preparing its local carers strategy, a Local Authority must take such steps as it considers appropriate to involve carers.’ Whilst we applaud the positive intentions here, we are concerned that, in the absence of consulting with carers being made a duty on Local Authorities within this process, it may not routinely and formally take place. If this is the case, local carer strategies may not be adequately informed by the needs of carers, and in turn may not be successful in supporting them effectively.

3.3.3. Headway believes that involving carers in work towards local carer strategies should be a core part of the process, and as such that the Bill should be altered to ensure this. We additionally believe that consultation methods should be adapted to the needs of carers. In the instance of those who provide care for brain injury survivors, they may have little time to attended focus groups, for example, and so we urge Local Authorities to work with carers to establish the best ways to obtain their views.

3.4. Review of carer support plans

3.4.1. The Bill states that information would be contained within Adult Carer Support Plans as to the circumstances in which they may be reviewed in Pt2 s8 (1) (i). However, Headway would like these to be detailed in the Bill to ensure that they are broad enough for carers to be able to seek a review of their plan when reasonably appropriate. Without this, we are concerned that the circumstances in which a review may be sought could be ambiguous or set at a threshold which would not be supportive of carers in need.

3.4.2. We would also like the Bill to place a duty on Local Authorities to review these plans at regular intervals. Headway believes this is very important, as we are aware from our work with carers that many see their role as a duty, and consequently some are reluctant to speak up when their situation has become overwhelming or if they are struggling as they fear ‘failing’ the person they care for. Regular, systematic reviews would help this as they would identify any problems that the carer may struggle to admit to.
3.5. **Information for carers**

3.5.1. Headway believes it is very important that carers are able to access information and advice that will help them to proactively seek advice and support, and as such a duty on local authorities to provide this is welcome.

3.5.2. However, we ask that the Bill be amended so that, instead of establishing and maintaining an information and advice service, local authorities are able to either set this up, or support an existing service where this already exists and meets its standards. This would avoid duplication of effort and resources, and would avoid confusion should there be two sources of information. We also suggest that this service signposts carers to any specialist organisations that provide information for those supporting individuals which particular conditions, such as Headway for those caring for brain injury survivors.

3.5.3. As such, we support the National Carer Organisation’s suggestion that the wording of the Bill should be changed so that it reads ‘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.’ We also ask that information of this resource is proactively disseminated, as a number of carers are socially isolated and may not otherwise be aware that it is available.

3.6. **Paying for services**

3.6.1. The Bill states, in Pt3 s24, that Local Authorities would be able to charge for services and accommodation provided for carers. Whilst the Bill’s explanatory notes state that these charges would not be more than what the carer could practicably pay, Headway asks that information is made available clarifying what this means in practice, and how a person’s ability to pay will be assessed. This would help to ensure that carers’ finances do not become unfairly stretched as a result of them accessing support they need in order to continue their role.

4. **Is there anything that you would add to the Bill?**

4.1. There are two key issues that we would like the Bill to recognise and take account of; how carer services will be checked for quality, and emergency planning.

4.2. **Quality review of services provided to carers**

4.2.1. At present, there is nothing in the Bill to explain how local authorities will be inspected or appraised as to the services and support that they provide to carers. Headway would like to see explicit mention of this in the Bill so that it is clear to both local authorities and carers how performance will be managed here.

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2 As stated in the National Carer Organisations’ paper, ‘The Carers (Scotland) Bill – A briefing paper for carers, 2015, pp. 2-3.
4.2.2. Such provision will help to ensure that there is no ambiguity, and will demonstrate the commitment to delivering support for carers in the manner intended. We believe this process should be independent, and that the views of carers should be taken into consideration.

4.3. **Emergency planning**

4.3.1. Headway believes that the Bill must contain a requirement for every Adult Carer Support Plan to cover what will happen in an emergency. This will ensure that carers are supported in knowing that, should they reach a crisis, they will be able to find support and advice. We feel this is supportive also of the person being cared for, as it will ensure that the carer is supported to be able to return to their role as quickly as possible.

4.3.2. We understand that this can be a particular concern for older carers, whereby many worry what will happen when they are no longer able to care for their loved one through old age, illness or death. By including a section within Adult Carer Support Plans on emergency planning that covers this difficult area, many carers will be given greater peace of mind that there is a pathway in place should they become unable to continue in their carer role.

4.4. **Waiting times for assessments**

4.4.1. Headway also asks that the Bill mentions waiting times for carer assessments and, ideally, a maximum length for these. We understand from our work with carers that, under existing provisions, many have to wait unacceptable lengths of time to be assessed for support. This can be frustrating and distressing for carers who feel that they need help. By adding a duty about waiting times the Bill would provide greater reassurance to carers that timely support is accessible.

4.5. **Relationship support**

4.5.1. The charity would like any resulting carer support plans and provisions to include relationship support. We understand that, when a person becomes the carer of a person they are in a couple relationship with, the dynamic can change considerably. This can place a great deal of emotional stress on the carer and their partner, and can lead to relationship breakdowns. Supporting the carer in their relationship – emotionally and sexually – can help them to adjust to their situation and to maintain their relationship where appropriate. This can also improve outcomes for the person they care for.³

5. **Is there anything that you would remove from the Bill?**

5.1. Headway would like to see the Bill amended along the lines it has detailed above. Aside from this, we are broadly pleased with the ethos of the Bill and what it seeks to achieve for carers. We believe it could provide valuable support for those caring for brain injury survivors, and are pleased to

³ This is explored in detail in Relate’s recently published report, *The Best Medicine*. Headway supported the development of the campaign launched alongside this, and backs the campaign.
have had the opportunity to share our views with the Scottish Parliament Health and Sport Committee.

Headway