Carers (Scotland) Bill

The Coalition of Carers in Scotland

The Coalition was established in 1998 and represents over 90 local carer organisations. We are the largest network of local carer organisations in Scotland.

The Coalition’s priority is to promote carer engagement and represent the carers’ voice in national policy discussions. We have a proven track record in engaging carers in consultation to inform the development of social and health care policy.

Carers welcome the government’s decision to introduce new rights and entitlement to carers through specific carer legislation. This is something which our members have been campaigning for over many years and the reason why we introduced the strapline ‘From Recognition to Rights in 2012.

Carers have also expressed severe disappointment with some aspects of the Bill and are concerned that in its current form it will not fully deliver its aims and could fail to make a genuine difference to their lives.

Our submission outlines the areas of the Bill that we feel must be strengthened and aims to offer solutions on how this can best be achieved.

How We Have Submitted Our Views

- We have submitted evidence from our Rural and Remote Carers Working Group outlining the additional impact rurality has on caring and setting forward best practice examples in supporting carers in rural and remote areas.

- We helped to develop and disseminate a joint Third Sector Positions Paper supported by the Health and Social Care Alliance, SCVO and condition specific organisations

- We have developed a joint submission with the National Carer Organisations, providing detailed evidence on the following areas where the Carers Bill requires strengthening:
  - Replacing local eligibility criteria with national eligibility criteria
  - Placing a duty on local authorities to provide a baseline level of universal, freely available services to carers in their area.
  - Strengthening the duty on local authorities in relation to short breaks beyond ‘having to consider whether an eligible carers support should take the form of a short break’. The duty must relate to providing a short break to eligible carers.
o Including a statement recognising carers as Equal Partners in Care

o Including a duty on health boards to inform and involve carers in hospital admission and discharge procedures

o Including emergency planning and future planning for carers within Carers Support Plans and Young Carers Statements.

o Fully recognising the role of the Third Sector, particularly local carer organisations in implementing the Bill

o Defining personal outcomes for carers beyond their caring role to recognise that they are entitled to a life outside caring.

o Placing a requirement on G.Ps to keep a register of carers and to be pro-active in signposting carers to support and offering them an annual health check

o Including a clear equality statement and action plan within the Bill.

o Making Health Boards jointly responsible for the development of local carer strategies

o Ensuring carers have a method of redress if they are unable to access their rights

o Supported the implementation of the Bill with adequate resources and clearly setting out what resources will be directed to carer support in Joint Strategic Commissioning Plans

In this submission we plan to take a broad overview of the Bill by drawing on the views expressed by our members through:

- An interactive session at our member meeting on the 25th of March, which was attended by over 70 carers and staff from local carer organisations. A full report is available as an Appendix

- Visits to local carer forums

- Opportunities via social media for carers to have their say.

We have also drawn on the responses to the consultation on proposals for carer legislation, which over 500 carers contributed to.

**Putting the Carers Bill in Context**

‘True partnership in operation means that the carer is listened to, the carer’s situation is improved, the cared-for person is happier and the carer is happier’. (COCIS member meeting)
Carers as Service Providers

It is important to put The Carers Bill in the context of the support that carers provide. There are an estimated 759,000 carers in Scotland.¹ The care that they provide is valued at over £10 billion each year², meaning that they provide more care than the entire health and social care workforce and private sector agencies combined.

Carers are not service users, rather they are unpaid service providers who are a valuable and finite resource and who require support to assist them in their caring role. This is essential to protect their health and wellbeing, minimise any negative impacts on their lives from caring and ensure that the caring role does not break down requiring more costly interventions from the state.

A comparison between unpaid carers and the paid care workforce

Many of the tasks carried out by carers are identical to those undertaken by the paid care workforce. They carry the same risks and should command the same respect. However, when we compare the rights and protection afforded to carers in comparison to the paid workforce there is a stark contrast.

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<tr>
<th>Entry</th>
<th>Paid Workforce</th>
<th>Unpaid Carers</th>
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<tr>
<td></td>
<td>Typically apply for the job, have a contract, choose to do it and can leave after giving notice</td>
<td>Typically unprepared, have limited choice but to carry on caring, face stigma for stopping</td>
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<thead>
<tr>
<th>Working hours and Holiday Entitlement</th>
<th>Paid Workforce</th>
<th>Unpaid Carers</th>
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<tr>
<td>Right to flexible working, to choose one’s hours; Working Time Directive protects worker’s ability to do the job safely, requires daily and weekly rest periods and breaks between shifts. Extra rights for night shifts Entitlement to a minimum of 28 days annual leave per annum (pro-rata for part time workers)</td>
<td>Carers have no statutory entitlement to a break from caring Rest Assured, A study of unpaid carers experience of short breaks found that 57% of carers had not had a break from caring</td>
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<tr>
<th>Pay and benefits</th>
<th>Paid Workforce</th>
<th>Unpaid Carers</th>
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</thead>
<tbody>
<tr>
<td>Minimum wage £6.50, living wage £7.85, HMRC mileage allowance 45p per mile, automatic pension enrolment, Statutory Sick Pay £87.55</td>
<td>Carers Allowance £62.10 per week (equivalent to £1.77ph for a 35 hour week). Less than SSP and JSA £73.10</td>
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<tr>
<th>Risk</th>
<th>Paid Workforce</th>
<th>Unpaid Carers</th>
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<tr>
<td>Protected by employer insurance and Health and Safety law, including right to consultation, training, equipment, protective clothing, risk assessment, limits on manual handling etc.</td>
<td>No protection. Aside from H&amp;S risks, carers risk having reduced quality and opportunities in life</td>
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¹ Scotland’s Carers an official statistics publication for Scotland, The Scottish Government, March 2015
² Valuing Carers 2011 Calculating the value of carers’ support, Carers UK and University of Leeds
## Wider Social Care Reform

It is also necessary to put the Carers Bill in the context of existing health and social care policy and legislation, particularly in relation to the ongoing social care reform agenda.

The integration of health and social care services, the re-shaping of older people’s services and the universal introduction of self-directed support aim to radically change the way services are designed and delivered.

The underlying principles of these reforms include shifting the balance of care to care at home and enabling service users and carers to have greater involvement in service design, both at an individual and strategic level.

These principles are welcomed. However, they have been introduced at a time when local authorities are implementing spending cuts across their services.

We have long stated that unless carer support is a one of the central pillars of service reform, the pressure and burden on unpaid carers will increase further.

Already we are seeing good intentions fail to materialise in practice. For example, while the Change Fund directed 10% of resources towards support for carers, local partnerships have not invested anywhere near the same level of support through mainstreaming projects or funding carer support through the Integrated Care Fund.

Similarly, while the Social Care (Self-directed support) (Scotland) Act provided local authorities with the power to provide carers with self-directed support, including a direct payment in their own right, very few have enacted this power. In fact a recent report based on FOI returns from local authorities revealed that only 3 carers in Scotland had been able to access a direct payment since the Act came into place⁴.

The current challenges in health and social care and their impact on carers make the Carers Bill ever more significant. But it must not be considered in isolation, or as the single solution to addressing the current deficits in health and social care policy in relation to recognising and supporting carers.

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The Carers Bill - A framework for Carers’ Rights and Carer Support

_We need common sense legislation that ensures equality and maintains standards of support_ (carer, North Lanarkshire)

Carers have welcomed The Carers Bill as a framework for recognising carers and providing them with an entitlement to support for the first time.

It sets out the process for implementing these new rights, from identifying carers and assessing their needs to setting out their eligibility for support.

All these steps need to be in place for the system to work and to deliver both consistently and equitably for carers. They need to be comprehensive, without being overly bureaucratic and they need to take account of the needs of the diversity of the caring population.

Where one step fails, such as carers not being identified, or informed of their rights, then the Bill fails to deliver on its intentions.

We feel there are areas where the Bill requires strengthening, both in terms of getting the process right, but also in ensuring that a focus remains on preventative support and that resources are not re-directed to carers who have eligible need to the detriment of carers who require early intervention. We therefore recommend the following

**Identification of Carers**

There are no specific provisions on the face of the Bill in relation to carer identification. This is a vital first step in supporting carers.

All agencies need to play a role in identifying carers and signposting them to support. However, G.Ps are in a unique position as they are frequently the first line of support. Carers are supportive of the idea of a G.P carer register provided it serves more of a function in supporting carers and is ‘more than just a flu jab’ (carer, North Lanarkshire)

Suggestions from carers for an enhanced G.P register include; access to longer and more flexible appointments, carer health checks, signposting to carers support services and additional support from an identified practice staff member.

**Provision of Information and Advice**

The duty on local authorities to ‘establish and maintain an information and advice service for carers’ (Section 31 Point 1) is welcomed. This will be best achieved by resourcing existing services that work with carers, and only establishing a new service if there is an identified gap.

Carers value the information and support they receive through their local carer centres and many were clear in their response to the Bill that information _should be provided by a local independent carers centre who can provide independent advocacy and advice, not by social workers_ (NCO survey).
Assessing Carers – The Adult Carers Support Plan
Carers welcome the new provisions relating to carers assessments with the focus on a personal outcomes approach, available to all carers ‘Previous Carers ‘Assessments’ in West Lothian felt more like an examination of the Carers Competence and ability to Care. I never felt it was supportive (NCO Survey)’

Again many carers indicated a preference for Adult Carers Support Plans to be undertaken by local carer organisations. ‘Carers centres are best placed to carry out carer support plans as what they do is all based around carers needs’ (COCIS member meeting)

The Bill includes provisions for local authorities to devolve this responsibility to third sector organisations and it is a model which already operates in many areas, including the Borders, Stirling and Argyll and Bute where the local carers centres undertake carers assessments within the local authority.

The advantage to this model is that the timescales for carers to access a Carers Support Plan are generally shorter and they are also able to access universal services provided by the carers centre, such as emotional support and training.

Consideration also needs to be given to the training of staff whose responsibility it will be to undertake ACSPs. There has been much learning over the last few years in relation to adopting an outcomes approach to assessing carers and using best practice models such as ‘Talking Points’. This best practice must be embedded in the new approach so that ACSPs do not become a bureaucratic, paper exercise.

Carers who do not wish to take up an Adult Carer Support Plan
‘A minimum offer of support, so that nobody receives less than the minimum (carer, West Lothian)

Adult Carers Support Plans will need to be promoted and carers will need to be made aware of their right to access one. However, it needs to be recognised that some carers will choose not to access one. In which case It is essential that such carers still have access to universal preventative support through their local third sector carer support organisations.

This may include attendance at their local carer support group, or attending a carer training course. For example, VOCAL Carers Centre in Edinburgh advertises their training courses online and carers are able to book a place without going through a formal process.

For some carers this is a first route into support, they may then choose to access a carers assessment, or additional services at a later date, such as when their caring role intensifies

Carers who access an Adult Carers Support Plan but do not have eligible needs
Extending the right to all carers to access a Carers Support Plan is a positive
thing. It should enable carers to identify their personal outcomes and what support works for them. It should also allow them to plan for emergencies and for the future, particularly where their caring role fluctuates or is likely to increase.

In some cases it may result in carers choosing to no longer continue in their caring role where this is the right choice for them and/or the person they care for.

Where carers have identified a need for support, but they do not meet eligibility criteria, it is essential that these needs are still given priority. But as carers have repeatedly questioned ‘Who supports those who don’t meet eligibility’ (COCIS member meeting)

We recommend that the Bill should specify that all carers should be eligible to a range of universal services, such as training, advocacy and emotional 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.

Since there is already a duty within the Bill to provide all carers with access to information, advice and a Carers Support Plan, there also needs to be a corresponding duty relating to a minimal offer of support, to carers who will not be eligible for more specialised services. Otherwise there is a danger that there will be nowhere for information services to direct carers to.

Our intention with this duty would be to protect and build on the existing network of local carer support services within Scotland which already exist in all local authority areas with the exception of very remote and island communities.

We will say more about universal services provided by the third sector later in this submission.

**Carers who have eligible needs**

‘National eligibility would provide a service across he board and it would not rely on the LA budgets to determine the level of service’ (COCIS member meeting)

For the first time carers who require support and who meet an eligibility threshold, will have a right to support

Eligibility criteria must be developed nationally, to ensure equitable provision across Scotland. We will provide further details on this later in our submission.

**Where carers are not able to access their rights**

‘Where a duty is put in place, it is important LAs adhere to it. There needs to be sanctions for those who do not provide carers with their rights.’ (Rural and Remote Carers Group)

One of the concerns that carers expressed was that they would be unable to access new entitlements through the Bill as this was their experience when
trying to access rights in relation to the person they care for.

It is vital that if carers encounter problems, that they have access to a method of redress that is easy to navigate and enables them to access their rights.

As it currently stands carers must go through the social work complaints system. If this does not prove to be satisfactory they can only complain to the Scottish Public Services Ombudsman. But this route is only available 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.

In our joint NCO response we have outlined recommendations for how carers should have access to a real method of redress, based on the findings of the Crerar Review.

**Universal Services and the Role of Local Carer Organisations**

‘The Bill needs to recognise the role carers centres play. I did not want to let anyone know I could not cope until I came to the carers group. They have helped so much to get my life back on track’ (Carer, South West Glasgow)

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 Point 1)

By general support we are interpreting this to mean support which is available universally within the local community, which does not require someone to meet eligibility criteria.

For carers, much of the support they access locally is provided by local carer support organisations. This support does not require them to have a statutory carers assessment, is universally available and is preventative, helping to sustain their caring role.

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 paragraph 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 counseling, 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. The value of these forms of support has been well evidenced and is summarised in the report ‘A Good Outcome’ Evidencing how local carer organisations are supporting carers to reach their personal outcomes’.  

To put this in context, only a small percentage of carers access statutory support following a carers assessment, with the majority accessing support through universal services.

Furthermore, with an increase in the number Adult Carer Support Plans being undertaken there will be a corresponding increase on the demands on universal services.

It is therefore essential that these supports continue, are properly resourced and that they are not defined too narrowly.

**The Carers Bill must deliver equity! – National v Local eligibility criteria**

‘Abolishing the postcode lottery is essential to implementation. The Scottish Government should take a stronger, firmer stance with local councils’ (COCIS member meeting)

There is a broad consensus among carers and carer organisations across Scotland that the Bill’s provision for a duty on local authorities to provide support to adult carers based on local eligibility criteria is insufficient, unhelpful and designed to perpetuate the existing postcode lottery.

Carers were explicit in their response to the consultation on carers legislation that they believe eligibility criteria must be national rather than local. They stated that this is the only way to avoid a postcode lottery and to ensure that carers have access to the same rights and entitlements across Scotland.

If local authorities only have a duty to develop local eligibility, carers will be at the whim of 32 different systems operating across Scotland. 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.

The reasons that carers have given for wanting national eligibility criteria are outlined in the briefing paper 5 CLEAR reasons for national eligibility criteria.

The arguments that the government and COSLA have given for introducing

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local eligibility criteria are:

- Local criteria supports local variation
- Evidence suggests that local criteria has been more successfully implemented in the past.

We fully support the concept of best local practice and 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 and island communities where transport and accessibility are a greater concern.

However, we do not believe there is any justification for a variation in the levels of need which trigger an entitlement to support. There is no justification for not defining national standards of eligibility so that carers are able to access the same level of support where they have a similar level of impact and intensity of caring role.

‘The postcode has not a lot of bearance on caring. The impact of caring depends on the level of caring, how long you care for, the type of caring situation you are in. Not your postcode’ (COCIS member meeting)

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

In terms of other nations’ experience of implementing eligibility criteria, we have been unable to find any examples of countries developing local eligibility criteria for social care. England and Wales have recently introduced national eligibility criteria for care services and there are many examples of European countries with national eligibility criteria for social care, including carer support.

In research by the Universities of York and Stirling Rethinking, Social Care and Support: What can England learn from other countries, one of the key conclusions from the report was;

‘Eligibility criteria and assessment processes are also determined at national levels (although assessments may be carried out by local officers and organisations.) The clear role of national governments in generating, distributing and allocating resources significantly reduces the risk of local geographic inequity’

Scotland’s National Carer Organisations are currently engaged in a short term project to develop a framework for national eligibility criteria for carers. We are investing our own resources in this so that we can present a viable alternative to local eligibility criteria, which has been co-produced by carers. We will also involve other key partners, including representatives from health boards and local authorities in its development to co-produce a solution for broad

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consensus. We will be sharing this with government over the next few months.

The Need for Adequate Resources

More resources will be required or existing resource will be diluted (a see-saw effect) However, if done in partnership between local authority and health with pooled budgets it will achieve better outcomes for people (carer, West Lothian)

The Financial Memorandum sets out what the cost implications will be in relation to the implementation of the Bill and what resources will accompany it.

It is our intention to submit evidence to the Scottish Parliament’s Finance Committee on this. However, we have several questions in relation to the resourcing of the Carers Bill which we feel need to be considered alongside some of the issues we have already raised in this submission.

- There needs to be a clear indication of what the government will be providing as additional resources for carer support and what resources will replace funding which is coming to an end. This would include respite care funds (£2.28 million) The Carer Information Strategy Funds (£5 million) and the 10% of the Change Fund which was directed to carer support. If the costing in the Bill are calculated without taking this deficit into account the sums won’t add up.

- How will any new resources be directed to carer support, how will the government ensure that they are of direct benefit to carers and specifically used to implement the provisions within the Bill? As one carer put it ‘Who is to say that the money will be ring fenced and used for carers support??’ (NCO survey)

- Local authorities will need to invest both new and existing resources in carer support. However, since there have been significant cuts to carer services over the last few years there is the danger that new resources will only address the rollback of services we have already seen and we will simply return to the position we were in previously.

- The financial memorandum includes costings for additional posts in relation to the new duties within the Bill. For example, Table 70 outlines the costs associated with advice workers in relation to the duty to establish and maintain an information and advice service. It needs to be made clear that these workers will be additional to existing carer information and support workers to address the increased demands on services arising from the new duty.

- It is also not clear from the financial memorandum how the costs in relation to the Duty to Support have been calculated. It would be useful to have a breakdown of the separate elements, such as short breaks, carer training etc.
We are also extremely disappointed that the financial memorandum states

‘There are no direct duties on third sector providers such as local carer organisations in the Bill and therefore no direct costs on them arising from it’ (Paragraph 112)

As we have illustrated throughout this submission the third sector, in particular local carer organisations, will be instrumental to the successful implementation of the Carers Bill

The provisions within the Bill will directly result in an increased demand on their services, as more carers will be identified, undertake an Adult Carers Support Plan and require access to universal carer support services. Unless they are adequately resourced they will be unable to cope with the additional demands placed on them.

**Carers As Equal Partners in Care**

Recognition of carers as equal partners in care at all times, not just when it suits for them to be so. Recognition of carers as experts in their own situation. (COCIS member meeting)

The Community Care and Health Act 2002 recognised carers as ‘key partners in providing care’. This was further strengthened by Caring Together The Carers Strategy for Scotland in 2010 which recognised carers as ‘equal partners in care’

This has been a key shift in recognising carers as service providers who have an important role to play, both in service planning at a local level, but also as equal to health and social care professionals in their knowledge and understanding of the care needs of the person they look after.

The Carers Bill includes a duty on local authorities to involve carers in the planning, shaping, delivery and review of services, which is an extension of the current provisions within the Public Bodies (Joint Working) Act.

In addition it includes a requirement for local authorities to take into account the views of the carer when determining the needs of the person being assessed and deciding what services to provide and how to provide them.

These new provisions 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.

This recognition would build on the best practice developed through the Equal Partners in Care Project (EPiC). This is a national framework for professionals developed by the Scottish Government and NES, based on six core principles. The EPiC project supports workforce learning in health, social services and other sectors with a role in identifying and supporting carers. The recognition of carers as equal partners is a core value of this training.
Having their role and expertise fully recognised is an important factor in carer satisfaction and wellbeing. It is not something that requires extensive resources, rather it requires a cultural shift by professionals. By embedding the core principle of carers as equal partners in care within the Carers Bill this would provide a foundation for both the duty on local authorities to involve carers in service development and the requirement to take the views of carers into account in the care planning of the person they look after.

**Resourcing Carer Engagement**

It must also be recognised that carers require resources to enable them to participate meaningfully in local strategic planning and service developments. Our best practice standards, Equal and Expert, 3 best practice standards for carer engagement\(^6\) provide a template for how partnerships should be facilitating and resourcing carer engagement.

We recommend that these standards are reflected in the guidance accompanying the Bill.

**Short Breaks – The Cinderella Service**

’I had to kick, scream, shout to get what I have got, and even then I was told that these places were so hard to come by, and they are quite often kept for emergency cases. But my point was who is to say that I am not going to become an emergency case if I don’t get it? (carer, Rest Assured Study)

We endorse the detailed submission from Shared Care Scotland setting out how the duties in the Bill relating to Short Breaks must be strengthened.

With reference to the duty to ‘consider’ whether support should take the form of a break from caring, we are concerned about how this might be interpreted. Does a duty to ‘consider’ provide sufficient legal clarity to enable carers to challenge a local authority decision if they feel their short break needs have not been properly addressed?

The duty, as it stands, does not address the need for local authorities to actively plan to improve the availability, choice and flexibility of short break provision. Such a duty exists in England for families caring for disabled children and there is evidence this is having a positive impact.

We therefore support a duty on local authorities to provide carers who meet eligibility criteria with a quantified, minimum level of short breaks, which would be clearly stated in their support plan and which would be made available through the different self-directed support options.

The government has already stated that 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.

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Additional Duties to be included in the Bill

Hospital Discharge
Carers need to plan for taking the person they care for home, yet some hospitals give little warning. The carer is central to the success of keeping the person they care for being readmitted (NCO survey)

Despite the existing Scottish Government protocol on hospital discharge, practice across Scotland differs widely and this is very often to the detriment of carers.

Part of this problem stems from the pressure on health boards to reach even shorter targets in relation to delayed discharge. As a result health professionals are sometimes transferring this pressure on to family members through their insistence that patients are discharged before a discharge plan is in place and adequate services are available within the home.

This attitude was recently highlighted by research which found that 72% of nurses in Scotland feel families need to take more responsibility for their older relatives. 78% said they do not believe families should be blamed if there is not enough support in place. This means that more than 1 in 5 nurses believe that family members should be blamed if there is not enough support in place.

Where necessary, support must be provided to the carer to ensure that their views are taken into consideration. For example, Stirling Carers Centre has a dedicated support worker, based within the local hospital whose role is to support carers to be fully involved in hospital discharge procedures and in making the transition home. Appendix Two in our submission includes a case study showing the positive outcomes this can deliver, both for the carer and the person they care for.

To create sustained and consistent improvement, which we believe would benefit both carers and those they care for, the national carer organisations advocates that hospital discharge 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.

We therefore support the addition of a duty on health to inform and involve carers in hospital admission and discharge procedures

Emergency Planning
‘We had a recent experience which showed us that, while we all hold a good deal of information about my sister’s routines and needs, there is a great deal

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7 Let’s Stop Going Home Alone Campaign, RVS, March 2015
only in my Mum’s head. It probably would be a good idea to work with her to get it all written down. *(ENABLE Scotland, Picking up the Pieces)*

We support the submission from ENABLE Scotland calling for a specific provision on the face of the Bill on emergency planning within Section 8 and Section 13.

Even when it is not enacted emergency and future planning provides peace of mind for both carers and the people they care for, allowing them to make decisions about future care arrangements before they reach crisis point.

**Avoiding Unintended Consequences - specific changes to the wording of the Bill**

There are several areas of the Bill which we feel need to be re-worded to avoid unintended consequences

- In the section **Key Definitions Part 1** the Bill should include reference to supporting carers in two additional ways: - to enable carers to disengage from caring (should they identify that as the main desired outcome) and to support carers post-caring

- The Bill sets out a duty on local authorities to ‘establish and maintain an information and advice service for carers in its area’. *(Section 31 (1))*. We are concerned that local authorities will interpret this as needing to establish a new service, put services out to tender, or bring them in-house. We feel it would be better worded as ‘the local authority will have a duty to maintain an information, advice and support service for carers and young carers, or establish a service where required’

- In relation to the requirement for local authorities to set out a timescale for preparing ACSP in their local carer strategies. *(Section 28 (f))*. We think this requirement would be strengthened by the phrase ‘reasonable timescale’ to convey the need for ACSPs to be undertaken within a prompt and reasonable timescale

- The definition of ‘personal outcomes’ for carers within the Act needs to be strengthened. More details of this are included in the NCO Joint response.

- The duty to take account of the care and views of carers in assessing the needs of a person (the cared-for person) is welcomed. However it needs to be made clear that the intention is to take account of the care that the carer is ‘willing and able’ to provide. Local authorities must not use this as a deflator in reducing the allocated budget for the cared-for person. This must be made clear in guidance

- **Section 24** of the Bill relates to charging for support provided to carers. It should be made clear that there is no intention to reverse the regulations in the Social Care Act in relation to waiving charges for carers.
Conclusion

Carers want a strong bill which will have a positive impact on their lives. To do this it must deliver clear rights and do so in an equitable fashion.

The role carers play in the delivery of health and social care will only increase in the next few years, as will demands on health and social care services. Carers must not be expected to shoulder an increasing burden. We are already seeing evidence of this with the 2011 census figures showing a marked increase in the number of hours carers are caring for.

This Bill should not be viewed primarily as a means to set out the process of providing carers with support and services. It must go beyond that and set out the principles by which we recognise carers as equal partners.

There needs to be a more balanced equation, where we value carers’ contribution and expertise, not with empty thanks, but by providing them with the resources they require to assist them in their caring role and to ensure they have a life outside caring.

The Coalition of Carers in Scotland
Appendix One

Report from the Coalition of Carers in Scotland member meeting
25th March 2015

Members of the Coalition of Carers in Scotland discussed the Carers (Scotland) Bill at their meeting on the 25th of March. This included an interactive session using message boards, providing participants with the opportunity to share their views on the Carers Bill, with a particular focus on whether eligibility criteria should be national, or applied on a local basis.

This is a report of the views expressed by our members. Just over 70 people attended the meeting and this was a mixture of carers and staff from local carer support organisations. The report sets out the questions posed via message boards and the responses received.

I support the introduction of National Eligibility Criteria

Strongly Agree 43

Agree

Don't know 1

Tell us your reasons why:

- To make all health board / local authority areas equal
- Local eligibility criteria could be used as a cost cutting exercise by Local Authorities
- Should lead to more equality away from party politics
- There has to be national eligibility criteria or things will remain the same with care being a postcode lottery and Local Authorities interpreting the Act to suit their criteria
- Employment rights are not left to individual companies, childcare provision is not entirely left to local authorities. Other national criteria includes free personal care, national care standards, housing support rights, education of children, if left to local authorities, why carers rights!
- To ensure fairness for all carers
- This should provide some equality and constancy rather than the 32variable interpretations of the law
- Implementation of the carers rights charter is essential to the working of the act
- Minimum national eligibility standards will ensure that local authorities have to provide at least a minimum level of support
• Do away with postcode lottery. Minimum criteria is necessary
• It will mean equality – not necessarily the loudest voice!
• The professionals frequently cause us more stress than the ones we care for with the stupid rules they make

I support the introduction of Local Eligibility Criteria

Strongly Agree 3
Agree
Don’t know

What principles should be embedded in eligibility criteria?

• Fairness, respect, equality
• Recognition, honesty and listening to carers
• Respect, listen to, honesty
• Basic criteria – if it set too high then no one access resources
• Recognised and valued for the crucial role they play and the sacrifice they give. We are all heroes
• Carers willingness, respecting carers as equal partners, listening to individuals
• Recognition at the start of caring and support and understanding no matter how long my caring journey took
• Capacity building in communities (carer today is tomorrows cared for) Valuing carers and ex-carers and benefitting from their knowledge and experience
• Recognition of carers as equal partners in care at all times not just when it suits for them to be so. Recognition of carers as experts in their own situation
• Should include some aspect of prevention – early intervention to avoid need for crisis intervention and the effect that has on the individual/family
• Respected and supported by all agencies as a carer
• To be treated as an equal partner in care (2 responses)
• Recognition, fairness, support for carers young or old no matter what their caring role is
• Focus on prevention – by providing universal access to some carer supports it will inform and enable carers to continue caring and keep well themselves

• There needs to be a minimum national criteria – to ensure equity and enable hard to reach groups to access support

• The criteria should make short breaks available to as many carers as possible

What would fair eligibility criteria look like to you – what would it include?

• All to be valued and recognised

• Support all carers as some may cope better than others

• Provide more support to a loved one than would normally be expected

• Knowing the different support available

• Criteria to prevent crisis – universal right to needs being assessed with Adult Carer Support Plan in place

• Bereavement – carers who lose the person they care for continue to be supported and assisted to adapt to life outwith the caring role

• Services should be delivered at the right time and address need

• Recognition we also may have other family members to support

• Minimum standard agreed by all stakeholders as acceptable baseline, recognition that good practice would be to raise provision above national standard level

• Universal and open to all unpaid carers with variations in levels according to needs assessment

What areas of The Carers Bill do you feel most need to be strengthened?

• Respite – Carers to be given the same holidays as an employee – 28 days

• Respite – Duty as a statute to all local authorities

• I feel more understanding of mental health and the very difficult job M.H carers have. It is so different from other caring

• Inclusion / involvement of health board and 3rd sector
• A key driver in carer support needs is hospital admission and discharge. The process of reviewing care support plans needs to include reference to this important change

• Support for hospital discharge duty. Example of good practice from NHS Tayside. Bad examples from NHS Lothian

• Inclusion of health to involve carers in hospital discharge

• We need basic eligibility to avoid crisis with funding resources out in place

• Carers having a length of their own. Stipulating why, when and how they will provide support. This needs to be recognised

• I am concerned that the parliamentary process is turning simple objectives into an overly detailed structure which risks swamping the original intentions of taking forward carers rights

• LAs should not be allowed to establish services if carer centres are already there and are doing good work

• Respite open door policy.

• Who settles on the desired personal outcomes? Is the final say so with the carer? The key word is personal

• Can the Bill go through a poverty impact assessment? The policy memos assessment on carers and deprivation levels is stark. What can the provision in the bill do to ensure carers in most deprived quintiles are as well supported as those least deprived?

• Can there be a requirement for monitoring and reviewing needs at the request of the carers. Could the adult carer support plan be named 'my carer support plan' with it being signed off and owned (primarily) by the carer

• There needs to be aggregation of identified needs in plans

• Carer involvement – the provision should be a duty to support the involvement of carers

• Local carer strategies should be required to abide by EPiC principles and provide 5-10 year forecasts on carers needs / trends

• Timescales for assessments to be carried out

• Support for hospital discharge

• New act says consideration must be taken regarding if a carer needs a break – but should there not be a duty to provide some sort of break
• The Bill talks a lot about ‘services’ we need to be careful this does not make carers ‘service-users’ – they are care providers. This needs reinforced throughout the guidance

• Carers should be supported if they no longer wish to care for the person they look after. For example, if they want to go back into employment

• Review of Carers Support Plan must be fixed time after completion by law

• Carers are not listened to when at meetings. We find the minutes don’t represent much of what we said. We turn up to find the meeting has been cancelled but they didn’t think we were important enough to tell us

• Emergency care planning should be made available to parent carers. But thought needs to be given on who will provide this and how it will be regulated

• Emergency care plans need to be part of the Bill

• Emergency care plans should be compulsory as it protects the cared-for and takes pressure of the carer

• Regular health checks should be available to carers

• Multiple caring roles need to be recognised in legislation

• The Bill needs to recognise the role carers centres play. I did not want to let anyone know I could not cope until I came to the carers group. They have helped so much to get my life back on track

**What areas of The Carers Bill are you most pleased about?**

• The removal of regular and substantial (3 responses)

• Duty to provide Adult Carer Support Plan (3 responses)

• Focus on young carers

• Getting the Bill/Act for carers to this stage is great news in itself

• Carers rights being recognised

• Carers recognised and their voices taken into full consideration

• Importance of legislation which will mean a **duty** to provide support to carers who fit eligibility criteria

• Recognition that carers should have rights
• The fact that the Scottish Government has recognised the need for supporting carers and also recognising the very important resource carers are to government and local councils

• That there will be a Carers Act eventually

• Recognition for carers at long last

• Carers recognition – duty rather than a power

• Carers having a say at last

• Lots! – That it exists enables a full societal discussion with potential for real benefits for carers as the eventual product

• Just to get to this stage is fantastic

• 3 areas – 1. Support plan 2. Recognition of emotional impact and support for emotional aspects of care 3. Recognition that it needs to be financed-good investment – big returns

• Carers rights, embedded in legislation for the first time

CLEAR Reasons for National Eligibility Criteria
Carers want National Eligibility Criteria. Do you agree? Share your views

• Yes, it is important everyone is treated in the same way – one process

• Does away with the postcode lottery

• National eligibility would provide a service across the board and it would not rely on the LA budgets to determine the level of service

• Yes, but it needs to be funded and resourced properly. A national framework should eradicate the postcode lottery

• Will COSLA hold the key to unlock the door to the development of a national eligibility criteria?

• I agree with national eligibility criteria. It sets a baseline for everyone

• National eligibility would ensure all regions are equal and the onus of responsibility is on the local authority

• Yes, but there needs to be adequate resources (financial) to support local authorities needs to be addressed

• Carers have to support each other and stand together to get the Bill through, along with any amendments as required

• There will be a postcode lottery if there is local eligibility
• Don't give LAs loopholes to be able to ignore carers

• There needs to be flexibility within a national framework

• EPiC principles should form the basis of national eligibility criteria. The principles are based on core outcomes, can accommodate local variation and form the basis of national standards

• We carers must be regarded as equal across the country

• Concerns about the dilution of good services, bringing services down, not bringing them up

• I agree because it wouldn't matter / depend on your postcode to get equality

• There should be national rights for carers

• Carer need to be recognised and national eligibility criteria will cover many carer who require support

We need to learn from other countries? Share your views

• This is a good gauge to see how other countries work with carers and how we work with carers. We should always be open for change and improvement

• Scottish Government must take this opportunity to implement best practice of other counties within Europe

• We cannot be narrow minded – must take heed of good practice

• Yes, it is important to learn new ways and work together

• Learning comes from many sources

• This should be an opportunity to look at the best practice in other countries and combine this with our own best practice

• Yes, it’s good to learn what’s positively working well elsewhere

• Yes, learning is good, but also learning what not to do?

• We should take this as good advice

• Learn what is most likely to work and be fair. Stop re-inventing wheels

• I think it is important to look at what other countries are doing and learn from them
Equity – A fair system. Do you agree? Share your views

- National eligibility standards would give clarity against which both carers and councils could judge how much was needed and what the shortfall was
- National criteria will address issues for all groups and will remove it from party politics
- Yes, equity should be for all care groups across Scotland. Fairness for all groups is required
- Don’t leave it to LAs, all carers should be treated equally
- Would not rely on party politics and LA budgets. Services would be a right and not a privilege
- Hard to reach groups find it difficult to have their voice heard. National criteria could help with this
- Should not be party political, depending on the ‘colour’ of the council. National criteria would avoid this
- National criteria will make it a fair system. Everyone will be treated equally
- Would help to standardize resource allocation
- Needs to apply to all care groups
- For as long as there have been services/support there has been issues. An equal and transparent system would allow areas to plan appropriate support

Abolishes the postcode lottery. Do you agree? Share your views

- The postcode lottery needs to be abolished so that it is fair all over and equal
- Yes, definitely agree. Clarity for all right across the country = better use/less waste of resources
- To be listened to it requires many voices and many different types of carers as there are many caring roles
- The national standards should be applied across all LAs But discretion must be applied only to increase the level of support above the national standard, never to decrease it
- Universal and open to all unpaid carers with variations in levels according to the needs assessment
• Universal for all carers with greater support available for those most in need

• This is crucial in a fair society

• The postcode has not a lot of bearance on caring. The impact of caring depends on the level of caring, how long you care for, the type of caring situation you are in. Not your postcode

• It needs to be a duty for local councils to provide resources and support to carers and monitor the situation

• Yes, it is important the system is the same for every carer

• True partnership in operation means that the carer is listened to, the carer’s situation is improved, the cared-for person is happier and the carer is happier.

• Agree strongly. Carers’ issues are of national concern

• There is a need to abolish the postcode lottery, fairness for all carers is a must. Some carers are not in the position to move home to receive quality support

• All authorities should have the same system. No carer should feel that they have to move or do without services

• Equal Partners in Care needs to be reflected in the development of any framework

• All carers should be entitled to the same services no matter what area they live in

• I Support the need to abolish the postcode lottery

• Abolishing the postcode lottery is essential to implementation. The Scottish Government should take a stronger, firmer stance with local councils

**Rights – available to all. Do you agree? Share your views**

• I think all carers should have the same rights

• Should be monitored to ensure it is happening

• All carers should have their rights and should know their rights and entitlements

• Yes, carers will be able to be confident in asking for support

• All carers should have the same rights and entitlements
• Some can cope with a little support, others need a lot. All should have the right to state what they can and can’t cope with. Rights for all!

• It should be a duty of care for all councils to provide care and support and monitor the carers situation

• We are all part of the same system. Our needs may vary but we still need support!

• Yes to rights available to all carers no matter who they care for, be it mental health, learning disability, young or old. They should all be treated the same.
Appendix Two

Stirling Carers Centre – Case Study – Hospital Discharge Support Service

Background
James was referred to the Enhanced Discharge Carer Support Officer by the Specialist Occupational Therapist working with his wife. Shiona had had a stroke and was elderly and frail. Shiona had been in the community hospital for some time, and had been discharged home previously but had to be readmitted. James’s caring role included personal care, a lot of emotional support and physical support and supervision. All administrative tasks and appointments were dealt with by him. He is also elderly and frail, and has not had a caring role in the past so was unsure of the details of the process and had felt lost in the past.

Action
The Carer Support Officer met with James, and had a person-centred conversation about his caring role and how the carer felt his caring situation could be improved. Using this information, a Carers Assessment was completed to depict the nature of his caring role and to request services that he felt would help his situation. He expressed that he would like to be able to talk to other people in a similar situation and also that he would like to be able to get a break from his role to rest and recuperate. He then explained that he found the discharge process to be complicated and would like to know more about it, so that he felt prepared.

The financial implications of caring were also taking a toll on him, as Shiona was weak and very thin as well as being incontinent. James had to have the electric fire on all day, purchase incontinence pads and special foods for her due to her poor swallow.

Partnership working is key for smooth delivery of support for carers, and so the Carer Support Officer met with an Anticipatory Care Nurse, who completed a Single Shared Assessment for a programme of regular respite in residential care.

A conversation about benefits was had between the Carer Support Officer and James, and following this, an application for Attendance Allowance was made together.

Result
- Information – the Carer Support Officer discussed the discharge process and provided contact numbers for the Carers Centre, NHS staff and Social Work
- Informal respite - information given by the Carer Support Officer on local stroke support group, Chest Heart and Stroke support and peer support groups offered by Stirling Carers Centre
• Benefits – Attendance Allowance was awarded at the higher rate

• Formal respite – residential care place granted by Social Work on a regular basis for James to have a break, and day care

Outcomes
James is now supported in his caring role. James was given the details of the discharge process and had the opportunity to ask questions, and had contact numbers for the Carers Centre, NHS and Social Work, so that he felt able to contact for support before his situation potentially reached crisis point. The regular breaks, and having other people to talk to who understand his situation means that he is happier and less isolated. He feels more able to cope as he has these mechanisms in place and is less likely to have to readmit Shiona because he is overwhelmed or exhausted. Shiona was discharged from hospital already having the Attendance Allowance application completed and ready to send, and following the award, they are able to go out socially together to maintain their relationship, as well as being able to have the heating on to keep her warm.