

## Carers (Scotland) Bill

### National Carer Organisations

#### Introduction

This submission is made on behalf of the National Carer Organisations. We are grateful for the opportunity to provide evidence to the Health and Sport Committee on the Carers (Scotland) Bill. This submission is considerably longer than usual evidence submissions. However this is simply as a consequence of seeking to include as much commentary and background as possible on the individual provisions of the Bill and to highlight areas for improvement and strengthening.

In preparing our submission we sought to reflect the views of carers from the many and diverse caring communities and caring situations across Scotland. During the consultation on carer legislation we consulted with over 500 carers, via a survey, member meetings, visits to local carer organisations and through social media.

Since the Bill was introduced to parliament we have again consulted with our members, producing briefing papers and facilitating focus groups and events. Through this we have gathered extensive information on how carers have received the Bill, what they like about it, where they feel it needs strengthening and most importantly, do they feel it will make a tangible difference to their lives? Our submission summarises and reflects these views.

#### A positive response to much of the Carers (Scotland) Bill

Overall the people we have spoken to welcome the Carers Bill. They are pleased that the Scottish Government has decided to introduce legislation to deliver new rights and entitlements to unpaid carers.

Carers and their representative organisations, locally and nationally, have been campaigning for carers' rights over many years. They particularly welcome that local authorities will have a **duty** to support carers who meet eligibility criteria, as the current **power** means that there is a great deal of variation across Scotland in the level of support which carers can access. There is also no clarity about what support carers are entitled to. We hope the Carers Bill will bring greater equity and transparency for carers and replace the postcode lottery of support.

We welcome the introduction of Adult Carer Support Plans. At the moment only carers providing care on a 'regular and substantial' basis are legally entitled to a carers assessment. The removal of this test so that all carers can access an Adult Carer Support Plan is welcome as is the removal of:

- the requirement that the person being cared for must be someone to whom the local authority provides a community care service.

- the reference to a carer's ability to provide care will be removed. Instead it will refer to a carer being 'able and willing' to provide care

We believe it is positive that there will be two routes to assessment with a carer being able to request one and the Local Authority offer one.

**Identification of carers through a range of routes will be critical, including reaching people who have not identified themselves as being carers.** We welcome the commitment that guidance will be issued on Adult Carer Support Plans, which will include information on the different stages of caring and the need for a review to address periods of transition and to ensure that emergency and future planning are integral considerations within any plan.

We welcome clarification that where the carer and the cared-for person live in a different local authority area, the local authority in which the carer resides should prepare the Adult Carer Support Plan and they will be responsible for the cost of providing any agreed support

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

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

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

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

## Further strengthening of the Carers (Scotland) Bill is needed

Carers have however expressed severe disappointment with some aspects of the Bill, with carers expressing the view that in its current form some parts of the Bill will not fully deliver its aims or make a genuine difference to their lives.

Key areas requiring 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 in hospital discharge, the omission of emergency and anticipatory care planning on the face of the Bill and the need for a stronger equalities focus.

In addition, establishing key baseline information and having in place a robust monitoring and evaluation framework prior to the Carers Act coming into force will be essential. Many carers we speak to are understandably cynical about the extent to which well-intentioned policy and legislation will make any material difference to them personally. Expectations are often raised only to be quickly dashed as promised improvements fail to materialise. Carers must be confident that this legislation will have ‘teeth’ and that responsible organisations will be held to account.

The following pages give an outline of our views on each of the chapters within the Bill, areas within these we believe require further action or amendment (noted in blue) and finally details of areas we believe require to be added to the Bill or for additional consideration.

*(Part 1, Section 4: Personal Outcomes)*

*(Part 1, Section 5: Identified Personal Outcomes)*

### Outcomes

Part 4, subsection 1 of the Bill defines personal outcomes as “...outcomes, which if achieved, enable carers to provide or continue to provide care for cared-for persons.” Subsection 2 enables Scottish Ministers to make regulations about personal outcomes including to define what outcomes may be personal outcomes and matters which a relevant authority is to have regard to in considering personal outcomes.

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

However, whilst we welcome the inclusion of personal outcomes and the recognition that carers have needs for support to enable them to continue caring, we believe 4(1) should be amended to better define personal

<sup>1</sup> Measuring personal outcomes: Challenges and strategies, IRISS Insights, no.12 (January 2012)

outcomes that to recognise carers not solely for their caring role but as citizens with aspirations.<sup>2</sup>

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

Such an amendment should be included on the face of the Bill and further defined in regulation. It may be helpful to, for example, refer to Talking Points<sup>3</sup>, which 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 which we believe would be useful in defining personal outcomes for carers within the Bill.

Quality of life cared for person	Quality of life for the carer	Managing the caring role	Process
Quality of life for the cared for person	Maintaining health and well-being A life of their own Positive relationship with the person cared for Freedom from financial hardship	Choices in caring, including the limits of caring Feeling informed/skilled/equipped Satisfaction in caring Partnership with services	Valued/respected and expertise recognised Having a say in services Flexible and responsive to changing needs Positive relationship with practitioners Accessible, available and free at the point of need

*(Part 2, Chapter 1: Adult Carer Support Plans)*  
*(Part 2, Chapter 2: Young Carers Statements)*

### Adult Carer Support Plans

The provisions in the Bill that establish adult carer support plans (ACSP) are welcomed by carers. Carers will be identified earlier in their caring journey, enabling them to access support at an early stage which may prevent crisis. 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. There will be 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 the potential for variation in the contents of the ACSP, which will lead to a 'postcode lottery' of carer

<sup>2</sup> Also referred to in policy memorandum "Wider Initiatives" para 15

<sup>3</sup> Also referred to in policy memorandum "Key Definitions" para 60 - Talking Points: Personal Outcomes, Practical Guide, Ailsa Cook and Emma Miller, Joint Improvement Team (2012)

support and carers' experiences of the ACSP. An adult carer support plan should be broadly similar across local authorities – research from the Learning Disability Alliance Scotland found that there is considerable variance in the way carers' assessments are completed and recorded across Scotland, which leads to inequity for carers at the moment<sup>4</sup>. The postcode lottery can be avoided if national eligibility criteria is put in place, as this will guarantee that adult carer support plans begin from the same starting point and that carers have access to the same rights and entitlements across Scotland. *(See later section for further discussion on this issue)*

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.

### **Young Carers Statement**

The Young Carers Statement (YCS) 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 must be distinct from a Child's Plan as not all young carers will want or need a Child's Plan. However, the YCS appears to be identical to the adult carer support plan and it is not clear how tangible the young carers statement will be. 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 any kind of caring role that can 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.

It is noted in the Policy Memorandum that there may be confidentiality concerns about the content of the YCS being available to the 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). If a named person was aware of the existence of a YCS but not about the specific content, this may be enough to ensure the young carer is supported in their caring role without having the specific detail within the statement shared with the named person. It has also been suggested that the content of the young carer statement could only be shared with the named person if it is essential to their wellbeing based on GIRFEC principles.

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<sup>4</sup> <http://www.ldascotland.org/index.php/self-directed-support/179-carers-assessment>

## Waiting times for Adult Carer Support Plan and Young Carers Statement

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

In addition to this we support the call by Marie Curie for mechanisms on the face of the Bill that allow automatic qualification for support for those 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.

We fully support the call from Marie Curie for a commitment of no more than seven days to prepare an ACSP for carers of those with a terminal illness.

*(Part 3, Chapter 1: Local eligibility criteria,  
national eligibility criteria)*

### Local v national eligibility criteria

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 who meet **local** eligibility criteria is insufficient, unhelpful and designed to perpetuate the existing postcode lottery. There is overwhelming support for a framework of national eligibility criteria for support on which further local enhancements can build and develop best practice.

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.

We believe it is also important to put The Carers Bill in the context of the support that carers provide. There are an estimated 759,000 carers in Scotland.<sup>5</sup> The care that they provide is valued at over £10 billion each year<sup>6</sup>, 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.

This support needs to be a rights-based, an entitlement based on national eligibility in the same way as the paid workforce has the right to time off work, good working conditions and measures to protect their health and safety. Unpaid carers want to move to a position where they can also say 'this is what I contribute and this is what I am entitled to' and where they are no longer at the whim of individual local practice.

Of all the amendments which carers have indicated they wish to see made to the Carers Bill, the one they feel most strongly about is changing the eligibility criteria from **local** eligibility criteria to **national** eligibility criteria.

The Carers 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.

In order to access this entitlement, carers must first meet eligibility criteria. In other words the 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 the preventative approach and make it harder for carers to access support.

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.

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<sup>5</sup> Scotland's Carers an official statistics publication for Scotland, The Scottish Government, March 2015

<sup>6</sup> Valuing Carers 2011 Calculating the value of carers' support, Carers UK and University of Leeds

The reasons that carers have given for wanting national eligibility criteria are outlined in the briefing paper<sup>7</sup> “5 CLEAR reasons for national eligibility criteria” including equity, rights and ending the postcode lottery.

The arguments that the government and COSLA have given for introducing local eligibility criteria are:

- firstly, that this supports local variation and
- secondly, that the 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. 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 which developed 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 points from the report was:

‘Equity – between people with similar levels of disability and regardless of where they live – is a key feature of arrangements for funding and providing social care in other countries’<sup>8</sup>

It also featured examples from several countries where they have sought to reduce inequity through national eligibility criteria:

‘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

<sup>7</sup> Coalition of Carers in Scotland, 2015 <http://www.carersnet.org/briefings/>

<sup>8</sup> Rethinking Social Care and Support: What can England learn from other countries, University of York and Stirling, 2008

the risk of local geographic inequity'<sup>9</sup>

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

*(Part 3, Chapter 2: Duty to Provide Support to Carers)*

### **Universal, preventative support for carers**

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. This is essential in ensuring a preventative approach is taken to supporting carers and protecting their health and wellbeing. In addition, the Bill makes provisions for all carers to access an Adult Carer Support Plan and information and advice.

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,

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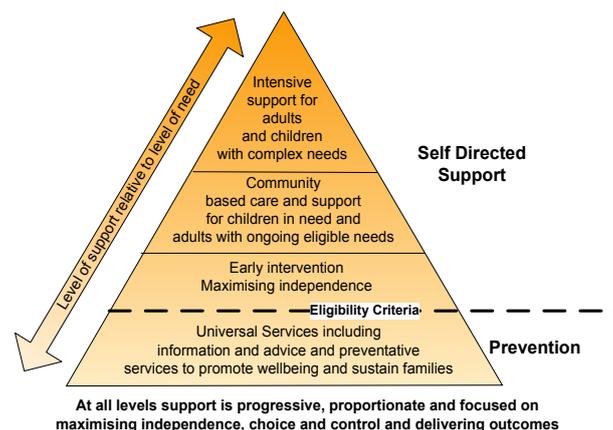
<sup>9</sup> Rethinking Social Care and Support: What can England learn from other countries, University of York and Stirling, 2008

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'*<sup>10</sup>

In addition, several local authority areas provide carers with a short break on a preventative basis through short break voucher schemes and through the government funded 'Time to Live' fund administered by Shared Care Scotland.

The diagram below provides an illustration of the role of universal, preventative services in supporting people. This model could equally apply in the context of the introduction of a duty to support carers.



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

Whilst carers should be encouraged to develop an Adult Carers Support Plan, and support services should aim to ensure that carers are able to access an ACSP should they wish to, there should be recognition that:

<sup>10</sup> *'A Good Outcome' Evidencing how local carer organisations support carers to achieve their personal outcomes*, The Coalition of Carers in Scotland, Evaluation Support Scotland, March 2015 <http://www.carersnet.org/wp-content/uploads/2014/06/Stitch-in-Time-Carers-Case-Study.pdf>

1. the process of delivering an ACSP (see pages 4-5) may take some time. Timescales for provision of an ACSP are not set and, as such, it may take some time for a carer to be able to access services and support. Universal, freely accessible services are vital to ensure that carers are able to sustain their caring role, health and wellbeing in the interim.
2. carers may not wish an ACSP at that time but instead may require small interventions such as peer support to sustain their caring role
3. carers may take time to identify themselves as carers. Self referral (or referral by another agency e.g. GP) to a carers support service may be their first step. It is vital that the process for accessing support in the first instance should not be overly burdensome.

The national carer organisations therefore recommend that the Bill should specify that all carers should be eligible to free access to a range of universal services including, for example, information and advice (which is already specified in the Bill), emotional and peer support and general carer support<sup>11</sup>. 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.

*(Part 3, Chapter 2: Provision of support to carers: breaks from caring)*

### **Short Breaks**

Providing opportunities to have breaks from caring responsibilities is now widely accepted to be vitally important in helping to protect carers health and well-being, and to sustaining caring relationships. For this reason we agree with government that breaks from caring deserve special prominence within the bill.

Government data and other research shows that the availability and choice of short breaks across Scotland varies considerably. Furthermore, we know from our own studies that carers often struggle to obtain information about the different short break services available in their area, and how these are accessed.

These are not recent problems, the Care 21 Report<sup>12</sup> into the future of unpaid care in Scotland highlighted these concerns and consequently promoted the vision, 'By 2014, carers will feel well supported and have a statutory entitlement to regular breaks from caring, with the cared for person, and have ready access to local practical support.'

The Carers Bill - in its current format - will not achieve these aspirations. There remains a gulf between the rights of the paid workforce and the unpaid carer workforce (which Scotland increasingly relies on to meet demographic change), which we believe must be addressed by the establishment of a clear

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<sup>11</sup> This list is not exhaustive

<sup>12</sup> Care 21: The future of unpaid in Scotland, Scottish Executive 2008

right to a break for carers. However there is much within the Bill that can be built upon to help improve carers' experience of short breaks.

In relation to short breaks the bill includes:

- as part of a general duty to support (referred to above), the Bill requires local authorities to give consideration to whether this support should take the form of a break from caring;
- a requirement on local authorities to prepare and publish a short breaks services statement which sets out the short breaks services available, which are relevant to the persons who live in that area;
- a regulation making power for Scottish Ministers to make further provisions about the preparation, publication and review of short breaks services statements<sup>13</sup>;
- a power on Scottish Ministers to make regulations about the forms of support that would constitute a break from caring. These regulations may make specific provision to deal with cases where the support is delivered through the provision of replacement care, or other services to the cared-for person.

During the initial consultation phase we argued that the Bill should contain a specific Duty on local authorities to provide and promote a range of short breaks to benefit carers and the people they care for. Such a Duty would require local authorities to plan and commission provision to ensure there is sufficient supply, choice and flexibility of short break opportunities to meet the needs of eligible families. We proposed that those not reaching the eligibility threshold would be helped with advice, guidance and information to access a range of mainstream services such as accessible recreational and holiday provision, as well as other inclusive community-based leisure activities. We also proposed the establishment of local support funds to help carers that don't meet eligibility criteria to receive financial help with a break, where they don't have the means to pay for this themselves.

The Scottish Government has decided not to include a Short Breaks Duty in the Bill. Instead the Bill contains a general Duty (Part 3, Section 22), to provide support to carers. In meeting this Duty local authorities must give 'consideration' to whether support should be in the form of a break from caring.

*"A local authority, in determining which support to provide to a carer under section 22 (4), must consider in particular whether the support should take the form of or include a break from caring."*

We welcome the general duty to support carers in the Bill but we are disappointed that government has decided not to take this opportunity to introduce an additional specific duty around short breaks. In our view, the

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<sup>13</sup> See later section on our response to short breaks statements

general Support Duty, as it stands, does not tackle directly the need for local authorities to actively plan to improve the availability, choice and flexibility of short break provision. Such a duty exists in England for families caring for disabled children (a requirement on local authorities to provide services to assist individuals who provide care for disabled children to continue to do so, or to do so more effectively, by giving them breaks from caring ) and there is evidence this is having a positive impact.

At the very least we would propose that a further addition is made to Section 28 on the preparation of local carer strategies to include specifically local authority plans for developing short breaks provision, taking account of current provision, an assessment of unmet need, and the demand for different types of break.

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

With reference to the duty to 'consider' whether support should take the form of a break from caring, we are concerned how this might be interpreted. In what circumstances might a local authority decide not to provide this support after consideration? 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?

We would prefer that those eligible for support, with have an identified need for a break(s), should be offered a quantified, minimum level of short breaks, which would be clearly stated in their Support Plan or Young Carers Statement, and which would be made available through the different self-directed support options. The government has already stated that adult and young carers should not be charged for the support they receive<sup>14</sup> - including any charges related to enabling breaks from caring - and we would expect this position to continue.

Section 8, 1(h) specifies that the Adult Carer Support plan should contain, '*information about whether support should be provided in the form of a break from caring*'. We would propose this is changed to, '*information about the support which the responsible local authority provides or intends to provide to the adult carer to enable a break(s) from caring*', and similarly for the Young Carer Statement (Section 13, 1(i)).

*(Part 6, 31: Information and Advice for Carers)*

## **Information and Advice**

Whilst we welcome a duty on local authorities to provide information and advice to carers, we maintain this is best achieved by resourcing existing

<sup>14</sup> Statutory guidance to accompany section 3 of the Social Care (Self-directed Support) (Scotland) Act 2013 and the Carers (Waiving of Charges for Support) (Scotland) Regulations 2014

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. SCVO's State of the Sector report found that expenditure on the services provided by the sector and the people it supports totalled £4.7 billion in 2013<sup>15</sup>. These services have often been established in a local area for many years and are well used, with many services operating at capacity. Dedicated carers' services in particular find themselves operating at capacity, with almost three quarters of services clear that they would not be able to cope with extra demand at their current level of resourcing<sup>16</sup>.

*“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 their local authorities; there are concerns that the Bill's introduction of a duty to provide information and advice will lead to resources being diverted away from carers' services in order to provide in-house services instead. Carers really value a dedicated, independent carers' service and are concerned that the Bill may encourage local authorities to establish a service in-house that provides information and advice on the points listed in the Bill but does not go above and beyond this in the way that carers' services do.

Despite assurances that local authorities will not seek to establish a service in areas where carers' services already operate<sup>17</sup>, the text of the Bill is ambiguous and we believe that Part 6/Section 31/Para 1 could be altered to recognise the contribution of independent carers' services and 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 to carers, or refer and signpost to specialist advice services, which 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.

In addition, these dedicated services offer a much wider range of services than information and advice. They provide vital support for carers who are

<sup>15</sup> <http://www.scvo.org.uk/wp-content/uploads/2014/04/SCVO-Sector-Stats-2014.pdf>

<sup>16</sup> Carers' services finance enquiry, Carers Trust Scotland and Coalition of Carers In Scotland, November 2014.

<sup>17</sup> 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.

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 information and advice services would not replace this.

### **The impact on the wider third sector**

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

The additional duties on local authorities to provide carers with information and advice and to support carers who meet eligibility criteria will inevitably result in an increase in the number of carers identified and a corresponding increase in demand for services. Previously hidden carers will begin to seek early and preventative support and as the majority of these carers will not meet eligibility criteria, it is likely that they will need to access universal support services provided by the third sector. The assertion in the financial memorandum that the Bill will not lead to direct costs for the third sector is flawed. Third sector services are already facing significant pressures due to the wider policy context, changes to funding and the impact of welfare reform (amongst other issues), and although the need for additional resources is recognised, this 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.

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 and particularly on carers' organisations. 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. The development process for Health and Social Care Partnerships' integration schemes has not always recognised the capacity of carers and carers' organisations; further capacity building will need to be undertaken to support carers and the third sector to engage in more effective ways when preparing local carers' strategies.

*(Part 6, 32: Short breaks services statements)*

## Short Breaks Statements

Part 6, Section 32 of the Bill requires each local authority to prepare and publish a Short Break Services Statement. This will contain information about the short break services available for carers and the people they care for. The Bill also gives Scottish Ministers regulation-making powers to direct local authorities on the preparation, publication and review of Short Breaks Services Statements.

This is another welcome development and one that we hope will go some way towards overcoming the difficulties faced by carers trying to access information about short breaks in their local area. However, we would expect a statement to go further than just a list of the “*different types and the range of short breaks that might be available*”.

It must include at least the following information:

- Details of the range and flexibility of local short break supports available, and how these reflect the needs and preferences of carers in the area
- Any criteria against which the eligibility for services will be assessed and the process which will be used to do this
- Details of universally available, inclusive recreation and leisure opportunities in the local area – including provision not subject to eligibility criteria
- Information about how short breaks will be supported through age and stage transitions
- An up-to-date list of key contacts for information and assistance on short breaks
- A named Lead Manager contact with responsibility for the Short Breaks Statement
- (Separate statements will be needed for Children’s services and Adult and Older People’ services.)

This will ensure greater transparency around how short breaks are accessed and allow comparisons between the different approaches to provision across the country, which may help drive up standards.

This information must be made widely available and we would therefore like to see local authorities being more proactive in promoting the choice and availability of Short Breaks in their area. Short Breaks provision should therefore be included in the list of information and advisory services specified in Section 31 of the Bill.

## Voluntary Sector Short Breaks Fund

Subject to Spending Review decisions, the government also proposes to extend the duration of the voluntary sector Short Breaks Fund. This Fund was developed by the National Carer Organisations in partnership with the Scottish Government and is administered by Shared Care Scotland. (The Family Fund administers a separate fund called Take a Break Scotland which

provides grants directly to families caring for disabled children and young people.) Between 2011 and 2015 the Fund has distributed £10.3 million to 613 projects benefiting 40,000 carers.

The continuation of the Fund is to be welcomed. The evaluation of the different programmes year-on-year has shown the considerable benefits the Fund is delivering to carers and the people they care for – many of whom may not have access to statutory services. The Fund cannot and should not replace the responsibilities of local authorities and health to support short breaks, but it can help to enhance and extend the provision available. Through the learning exchange programme, for example, the Fund is contributing to the development of new models of service provision, and is equipping services with new tools and information to help them become more sustainable.

### **Additional Strengthening to the Carers (Scotland) Bill**

By being added, we believe the following would strengthen and improve the Bill.

#### **(a) Carers As Equal Partners in Care**

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.

### **(b) Emergency planning**

We are concerned about the lack of emergency planning provision on the face of the Bill and believe the Bill would benefit significantly from the inclusion of a specific provision on emergency planning within Section 8 and Section 13. We would also propose a duty on local authorities to provide information and advice on emergency and future planning within information and advice services for carers (Section 31).

We are clear that emergency and future planning is a health and wellbeing issue for carers and the individuals they care for. The omission of emergency and future planning from primary statute is a missed opportunity to have a profound and positive impact on outcomes for carers and the people they care for.

ENABLE Scotland are funded by the Scottish Government to deliver their 'Picking up the Pieces' project which is analysing the impact of emergency planning, focusing on carer health and wellbeing and the reduced pressure on services. This is guiding their evidence submissions throughout the Bill process. We 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.

### **(c) Inclusion of Equal Opportunities Clause**

In taking forward the very positive developments in the Carers Bill, we believe that it could be further strengthened by the inclusion of an Equal Opportunities Clause.

Despite a legal obligation to 'promote equality of opportunity'<sup>18</sup> for individuals with one or more of the protected characteristics<sup>19</sup>, there is substantial evidence regarding differential levels of access to services for carers from minority groups including carers from Black and Minority Ethnic communities, LGBT carers and disabled carers. Despite commitments within 'Caring Together' to ensure actions are taken forward with due regard to "fully address the equalities perspective", this has not been evident across local authorities and health boards in Scotland.

Whilst 'pockets' of good practice exist, the NCO's believe it is time for a more concerted effort to focus the attention of local authorities and health boards on identifying and meeting the needs of carers with a protected characteristic.

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<sup>18</sup> Equality Act (2010)

<sup>19</sup> Equality Act (2010)

We would argue that all measures within the bill should be taken forward with due regard to promoting and encouraging equality of opportunity.

The number of BME carers has nearly doubled in the decade between the 2001 and 2011 Census with every local authority in Scotland seeing substantial growth in the number of individual BME carers residing in their locality.

Figures provided by the Scottish Government<sup>20</sup> highlight that women of working age are more likely to take on a caring role. 62% of carers between the ages of 25 – 49 are female. Given the heavily gendered bias, we welcome the strong Government focus on gender equality outlined by the First Minister. A key concern must be how the Bill will support women who are already experiencing a ‘carer penalty’ alongside more general concerns about the progression and status of women within the labour market

The Scotland Act (1998) allows for Parliament to legislate within parameters (as equality is a reserved matter) to ‘encourage’ equality of opportunity:

*“The encouragement (other than by prohibition or regulation) of equal opportunities and in particular the observance of the equal opportunities requirements” &*

*“The imposition of duties on Scottish public authorities, and cross-border public authorities in relation to their Scottish functions”*

We would recommend that the Carers bill utilises the above mechanism supported by robust monitoring and reporting processes. Local authorities and health boards should be required to develop a statement setting out how they will encourage equality of opportunity for those with protected characteristics to access and benefit from carer support services. Equalities data should be collected and submitted annually to the Scottish Government for monitoring against the statement and publication. Evidence of the process followed in delivering against the Statement should also be included.

The Scotland Act powers have already been utilised within the Regulation of Care (Scotland) Act 2001 and the Mental Health (Care and Treatment) (Scotland) Act 2003 amongst others.

#### **(d). Further recognition of wider policy and reform**

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

<sup>20</sup> Scottish Government (2015) *Scotland’s Carers: An Official Statistics Publication for Scotland*

organisations would welcome the opportunity to discuss this further and would suggest, that as part of the Bill, a requirement to consider the impact on carers of all policy across Government be considered (see 3. above)

Throughout this submission we link to such policies but in the first instance we would make particular reference to policy on delayed discharge and its unintended consequences for carers. The policy to reduce delayed discharge is important, but can, in some cases, result in inappropriate hospital discharge with increased carer burden (often without consultation or adequate social care support) and likelihood of readmission.

It is also important to recognise the wider context within which the Bill sits. In particular, the significant challenges faced in delivering social care services within reduced financial circumstances at both national and local government level.

Whilst we recognise these pressures, many carers face reducing care packages for the person they care for, support that is not delivered until crisis occurs, increasing charges for care that is provided and families supplementing the costs of care and adaptations where packages do not meet the full set of needs.<sup>1</sup>

This is not intended to be negative but simply to recognise the context within which the Carers (Scotland) Bill will be developed and implemented. The financial memorandum outlines a range of new funding to support the delivery of the Bill, which we welcome. However it is vital that these funds are protected to ensure that they do not simply replace existing social care budgets and deliver effective early support for carers, preventing crisis and enabling carers to have a life outside caring.

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

#### **(e) The NHS and General Practice**

It is proposed that the need for health boards to develop carer information strategies will be abolished. We believe the role of health needs to be further strengthened within the Bill. The Community Care and Health (Scotland) Act 2002 required Health Boards to develop a Carer Information Strategy (CIS). These strategies have been in place since 2008 and have been supported by funding, ringfenced for carer identification and the provision of information and support. (nearly £28 million to date)

There have been many positive outcomes arising from CIS funding, including early identification of carers from health professionals, signposting carers to

support organisations and an increased awareness of the needs of carers. In addition, funding has been awarded to carer support organisations to employ dedicated workers. For example, hospital discharge liaison workers, dementia support workers and older carers 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.

Carer Information Strategies have been a good way of ring-fencing money to support carers and there is a risk that Health Boards will not protect money for carer information, advice and training without this. Carer Information Strategies have also been effective in raising awareness of carers' issues within health services and we are concerned that without such a focus, that progress made will be lost.

*“Health boards are still slow to understand the needs and role of carers and involve them fully. The duty to provide information keeps them focused on the existence of carers”*

*“Carer information strategies help ensure that money is used for carers. It is essential that carers and carer organisations are included at strategic level.”*

We welcome the commitment to involve carers and carers organisations at strategic and locality level within new integrated arrangements but we remain concerned that this may not involve them in sufficient depth nor is it clear how this will inform the delivery of outcomes for carers. We believe that the mechanisms for directing resources to carer support, in lieu of NHS carer information strategies, must be nationally agreed and embedded within the new integrated partnerships to ensure that health boards and local authorities are able to respond to the requirements of their local communities.

We also welcome the Scottish Government's intention that health boards will be consulted in the development of local carer strategies. However, we believe that, in line with the integration of health and social care, these plans should be produced jointly rather than boards simply being consulted.

We have made specific reference to the role of health services on hospital admission and discharge below, however, the support of carers by health services links to the much wider policy agenda mentioned earlier in reducing health inequalities and improving health. As noted earlier, the national carer organisations would be keen to see such links made and an appropriate response made within legislation and guidance for the Carers (Scotland) Bill

General practice also has a vital role to play. In the original Scottish Government consultation on legislation reference was made to extending and consolidating the role of general practice in identifying and referring carers to support. However, the Bill does not bring specific provisions and the policy memorandum (para 122) notes that it “would be difficult to have a law about

identifying people who are carers”. It also recognises that the identification of carers is “hugely important as it is a prerequisite to assessment and support.”

The national carer organisations in our original response argued strongly that the role of GPs is critical and as such legislation and policy to support this requires to be strengthened.

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

The requirement to identify and refer carers was transferred into the core element of the GP contract in recent years, but the contract does not specifically mention a carers’ register. GP practices currently apply a code to an individual’s medical record within the practice if they are identified as a carer; collectively, this information can be used as the basis of a carers’ register.

The majority of carers (75%) who took part in our online survey felt that both local authorities and GPs should have a duty placed on them to identify carers. 17% of respondents thought that only GPs should have a duty placed on them, and only 5% of carers thought that the local authority alone should have a duty placed on them to develop and maintain a carers’ register.

*“GPs have knowledge of the people who are in a caring situation within a family and would be ideally placed to check with an individual that they are aware of the ability to have their caring needs met and supported. However, with 35 years of caring behind me, I was never approached about my daughter’s care needs since I had always just managed things on my own. Even when we were forced to look for medical interventions to try to help with my daughter’s emotional and behavioural problems worsening in the home, no support was ever suggested and we were never asked if we were getting any outside help (which we weren’t!) This means that more stringent measures would need to be put in place.”*

*“Important for things as basic as eligibility for flu jab etc. Helps GPs to be aware of stress and strain on individual patients.”*

The national carer organisations believe that there should be a legislative requirement for GP practices to develop a register of carers within their practice. The coding mechanism is already in place to enable a register to be created, but we think that there is limited value in creating a register if it is simply data collection. In addition to the identification of carers, GPs should be

required to proactively refer carers for an Adult Carer Support Plan, which should also be recorded on the individual patient record.

The carers' register should trigger an offer of an appointment for the individual carer every six months to determine if the caring situation has changed and whether additional support is required in terms of the carer's own health and wellbeing including an annual health check. There is currently some good practice in the provision of health checks for carers and carers are included in the Keep Well initiative (although we have limited information on the outcomes to date) but these should be implemented more widely and consistently. A legislative requirement to identify carers would assist and a method of measurement would also be required to ensure such activity is moving in a positive direction.

### **(f) Hospital Discharge**

Spending time in hospital, either due to an emergency or a planned admission is often a time of concern and additional stress for both carers and the people they care for. This is consistently the case, both when it is the carer who is admitted to hospital and when it is the person they care for.

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.

Where a carer requires hospital treatment this frequently means they are unable to continue to provide care while they recover, or sometimes, due to ongoing ill-health they may no longer be able to continue their caring role or may have to re-evaluate the level of care they can provide. It is therefore essential that at these times carers have access to information and support, from the point of admission to discharge and that their views are fully taken into account when the discharge plan is put in place.

There are a range of policies and protocols in place<sup>21</sup> to make the process of hospital admission and discharge run smoothly. These aim to ensure that patients receive the timely care in the right place and have safe discharge from hospital to a more appropriate setting.

Despite these processes stating that "patients and their carers are involved and supported in the discharge process" and that "the involvement of individuals, carers and family/representatives is an integral and essential part of admission, transfer and discharge management"<sup>22</sup> many carers continue to report that their experience of hospital admission and discharge is poor.

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<sup>21</sup> These include: The Planned Care Improvement Programme; Patient Flow in Planned Care; Admission, Discharge, Length of Stay and Follow up (2007), Guidance on choosing a Care Home on Discharge from Hospital (CEL32/2013), Admission, Transfer and Discharge (ATD) protocols (or something similar)

<sup>22</sup> NHS Forth Valley Integrated ATD protocol

In a survey of carers as part of the development of a Carers Rights Charter, the level of dissatisfaction in being treated as a partner in hospital admission and discharge was high. At these key points carers knowledge and experience of the person they care for is vital in helping to achieve the best outcomes for individuals nearly 40% said their experience of involvement on admission was poor or very poor and 45% said the same for hospital discharge.

*“It caused a lot of unnecessary stress following long periods of hospitalisation. A lot was due to poor communication. I would say in 5 out of 6 discharges I was made to feel I was a nuisance. I was really upset but I was too tired to go through the complaints procedure... and so I let it pass although I know I should have taken action.”*

*“Very poor, uncoordinated, last minute notice, suggesting to mum next day could be discharged then she was upset when it didn’t happen. When given phone call to collect mum, we sat ages in the ward waiting for discharge sheet, tried to read it again at mums house, It was scrappy and illegible.”*

Moreover, carers said they did not receive the information they needed on admission, diagnosis or discharge. More than 75% of carers said they did not receive the information they needed.

Despite Government policy aimed at reducing emergency and unplanned admissions, in research by Carers Scotland<sup>23</sup>, 40% of carers said they felt the person they cared for was discharged too early, with half of those saying this was the case because services were not in place to support them at home.

35% were consulted about discharge (but at the last minute) and 30% were not consulted at all! 60% said they were not given any choice about caring when the person was discharged. Three quarters were not offered any help with caring when the person was discharged.

**It has a direct impact on outcomes for patients, with nearly 20% readmitted within one month.**

*“It was just assumed I would look after my mother as she could not care for herself. No help was offered at all - they needed the bed so she was sent home. I told them she couldn’t look after herself and was told I would have to do it then!”*

*“I was assured that I need not worry about care, my wife needed carers to come (two handed) 3 times a day, I was given 5 days to find a care company. No help give apart from a book of care companies.”*

*“Poorly planned discharge - no referral for carers or district nurses, no equipment in place prior to discharge.”*

<sup>23</sup> Carers UK/Carers Scotland State of Caring 2014

*“It meant that she had to stay in bed and we had to shower and care for her and feed her in bed. I feel the carer should be consulted more. My father said he was ready to go home so he was discharged....I had to take 2 weeks off work to care for him full time.”*

*“I work full time as well as taking care of my husband who has MS. When he recently left hospital, I was not asked about the impact this would have on us, what help we had in place or if he would be able to manage in our home. He had to sleep on the sofa for 3 weeks following his release and had many bathroom accidents as both the bedroom and bathroom is upstairs and he ca not reach them. Very stressful for both of us.”*

### **Proposal for a Duty on hospital admission and discharge procedures**

The Scottish Government did not include this in its earlier proposals and it has not been included in the Carers Bill (as noted above). Despite the existing Scottish Government protocol on hospital discharge, practice across Scotland differs widely and very often is to the detriment of carers.

It appears that much of carers’ experience of hospital discharge has not improved greatly since the publication of “You Can Take Him Home Now”<sup>24</sup> in 2001. At that time, nearly three quarters of respondents were not given any choice over whether or not they provided care. Although two thirds had been consulted about hospital discharge plans, 43% felt that those arranging discharge did not take their concerns, ideas and comments into account. One in three people had to go back into hospital within 2 months of being discharged, with a third of carers saying this was due to them being discharged too early.

A carer then said: *“Everything we had been told had been arranged wasn’t so we had a horrendous first week”* and another *“Lack of communication about patient and no detail as to when discharge would take place. Also, patient sitting for hours waiting for transportation to get home.”*

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. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration.

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 national carer organisations therefore proposes the Health and Sport Committee examines our proposal, which is supported by carers, that a legislative duty is included in the Carers (Scotland) Bill to require health boards, and other relevant partners, to inform and involve carers fully in

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<sup>24</sup> Carers Scotland, You Can Take Him Home Now: Carers experiences of hospital discharge (Supplementary Report for Scotland), 2001

hospital admission and discharge procedures. This includes effective support where the carer has been a patient and requires appropriate recovery and recuperation time.

**(g) A real method of redress**

Carers report difficulties with obtaining redress through the social work complaints system. The social work complaint system is often difficult to navigate and carers have little redress outwith the local authority. They can only complain to the Scottish Public Services Ombudsman if there is maladministration or service failure on the part of the local authority. Beyond this carers could apply for judicial review but this can place a cost and risk to carers finances.

The Bill itself will deliver new rights for carers but it is vital that, should carers not obtain these rights, that a method of redress that is both easily accessible and delivers outcomes is in place.

To explain this fully, we refer to the following information taken from the Review of Procedures for social work complaints. “The Review of Social Work Complaints in 2011 recognised that the current system of complaints to social work required some reform. A key finding of the Crerar Review of regulation, audit, inspection and complaints handling of public services in Scotland, was that complaints processes are not always accessible or easy to use, are often complex and far too variable in their content. In short, they are not fit for purpose.

In response to the Crerar Review, Scottish Ministers established a number of groups to consider the recommendations in more detail, including the Fit for Purpose Complaints System Action Group. The report of this group, known as the Sinclair report, was published in July 2008.

Recommendations specific to social work were:

- Priority should be given to introducing standardised complaints processes in the sectors where there is the greatest risk to consumers from service failure and from which most complaints emerge - namely across the social care sector and across services provided by local government.
- The SPSO should work with local government and the Care Commission (now the Care Inspectorate) to develop complaints systems for social care and social work services which must include clearer communication about responsibility for handling complaints and better sharing of information on complaints.
- The number of stand alone complaints handling bodies should be reduced and functions should be transferred, where appropriate, to simplify the process and landscape for consumers. Specifically, Government should consider:

- Transferring the role currently performed by local authority Complaints Review Committees (CRCs) for social work to the SPSO.

This last recommendation was expanded upon in the report as follows:

*"The SPSO should take on the role of social work Complaint Review Committees (CRC). The current systems are based on statutory guidance from 1996, which gave each local authority scope to interpret how it should apply the rules. This has led to several different approaches being taken, and introduced complexity for consumers, and now needs simplification and updating. Government had already been considering reviewing the standard guidance issued to local authorities for handling social work complaints. A standardised system, within the SPSO would make the link between outcomes and improvements more consistent across the country and might possibly address the potential imbalance between the experience of complainants in larger and smaller authorities."*

*"[This would] ... make the overall process simpler and more consistently applied across councils. There needn't be any reduction in influence by social work or education professionals: any transfer of functions would be dependent on Chief Executives still being able to call on professional advice in determining cases at the local authority level."*

Implementing this recommendation would require a change to the law to widen the remit of the SPSO in relation to professional decisions made in social work cases. Additional resources for the SPSO would also be required. Currently the SPSO can investigate social work complaints once all the other stages of the complaint process have been completed. The SPSO only considers any maladministration or service failure (for example whether relevant policies and procedures in relation to a social work assessment have been followed correctly) but it does not have a remit to investigate professional judgement.

The SPSO has a remit over clinical judgement in relation to complaints about NHS services. If legislation provided for the same remit in relation to social work cases, the SPSO would be able to investigate the merits of a decision taken by a social worker in exercise of their professional judgement."

The Scottish Government response to this report recommended that the SPSO expanded its remit to take on a similar role to that of the Complaint Review Committees. This would provide the SPSO with a remit over social work decisions in line with its role in relation to NHS complaints.

We are aware that the Working Group was set up to consider this recommendation. However, we unclear of progress and when we may expect these recommendations to be implemented. We are aware that there are also considerations of how best to deliver a high quality complaints system within new integrated services.

The national carer organisations believe in order for carers rights to be enforceable and carers to have the opportunity to seek resolution and redress,

action must be taken to improve the review of social work complaints and indeed new integrated services.

## **Conclusion**

In summary, the national carer organisations broadly welcome the Carers (Scotland) Bill. The Bill has much to recommend it and will offer carers, for the first time, rights to support. Our recommendations intend to offer ways to strengthen the Bill further and to enhance both implementation and ongoing delivery of its provisions.

## **National Carer Organisations**

### **About The National Carer Organisations**

The National Carer Organisations are brought together by a shared vision that all Scotland's unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland and Shared Care Scotland.

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<sup>i</sup> State of Caring, Carers UK 2014 <http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2014>