

COMMENTS BY ADASS CARERS POLICY NETWORK ON MAIN PROVISIONS AFFECTING CARERS

General

The timescale for implementation of this legislation affords the opportunity for an extensive and inclusive approach to discussion of the provisions of the Draft Bill and the regulations and guidance that will accompany it. We accept the Draft Bill is the start of a process that will shape the way Councils and their partners understand and respond to people with care and support needs and their carers.

The current extensive policy and practice guidance reflects the complexity of the existing legal framework. It is essential that the regulatory and policy guidance in support of implementation of the Care and Support Bill in April 2015 is available at the same time. This was the approach adopted for the Children Act 1989 and was enormously helpful.

As with other aspects of the process the ADASS Carers Policy Network would see involvement in the preparation of regulations and guidance as one of the key areas of its programme for 2013/14 in support of the refreshed cross government strategy for carers issued in 2010. The overall approach of the Draft Bill and its focus on outcomes for people over 18, which includes carers and puts them on an equal footing, is supported.

Comments are made on specific provisions of the Draft Bill, as they affect carers. These are made with a view to enhancing the Bill in terms of the overall outcomes it seeks. In making these comments we recognise that further legal analysis of the Draft Bill is taking place on the interplay of its provisions as between its different sections and clauses to ensure consistency, clarity and coherence. We understand some technical issues/unintended consequences have been identified [for example S.41] and do not repeat them here.

The comments within this paper on issues affecting carers are, in general, consistent with earlier comments submitted on social care law reform. Those on young carers were joint with ADCS. With the exception of the provisions for transition for children to adult care and support the Bill excludes provisions for young carers. It creates the following serious anomalies:

- Parents of children with disabilities [unless they have their own care and support needs), must still request an assessment
- Children who are young carers must request an assessment
- It appears to introduce a new requirement that young carers must also be a child in need under S.17 of the Children Act 1989.
- Where young carers are identified there is no requirement to meet a parents needs for care and support to prevent, reduce or avoid the need for a child to

become or remain a young carer or the general principles we have adopted with ADCS.

We comment on these and other concerns about young carers in this paper and the value of co-ordinated and early cross government action to respond to them.

Comments on Specific Sections of the Draft Bill

Part 1 Care and Support – Section 1

The general provisions of Section 1 as they will affect carers are to be welcomed. We welcome the wide definition of well being in section 1[2]. Whilst supporting section 1[3] we feel there are three aspects that require further consideration for inclusion in the legislation or in a commitment for regulation and guidance. They are:

- Impact on carers
- Prevention
- Recognition of carers as partners in caring

[a] Impact on Carers

Specific provision is needed at this point on the need to consider the **impact** on carers in terms of care and support responsibilities that are important and relied upon. This needs to include their ability and willingness to sustain them. It is suggested that an addition to Section 1(3) might be made as follows:

- [x] Consider the impact of caring on the health, physical, emotional or economic well-being of a carer

The issue of impact is one that needs to find expression in other parts of the Draft Bill. We expect the work on interplay between sections to cover this.

[b] Prevention

The second point about prevention and reducing the need for care and support arising. In many ways the need to reduce the impact of care and support needs on people [including carers] is impact. Much of the Bill conveys the impression that it is about responding to carers and in supporting the continuation of their role. Both are important but there is a case for looking at the provisions of section 1(3) to see if its provisions can be more aligned with the national strategy and the provisions of Section 7 and those in Section 10(4).

We see this as particularly important in relation to young carers. Councils are expected to avoid inappropriate caring roles and reduce the need for young carers to assume or continue in such roles as set out in *Working Together to Support Young Carers and their Families* [2012]

[c] Recognition

The importance of recognising carers as partners in caring finds expression now in a range of current policy and practice guidance. Our own work on this shows, however, that at key stages along individual care and support pathways carers are not always recognised and treated as partners in caring. This is an issue for health and social care in terms of promoting their well-being. We would suggest inclusion of an additional provision in Section 1 (3) as follows:-

[x] recognition of carers and their capacity to be partners in caring.

Part 1 – Care and Support – Section 2 – Information and Advice

These provisions as they relate to carers are to be welcomed. Accessible and personalised information and advice at the appropriate time and in the right way is enormously important to carers. This is reflected in the national strategy. There are three issues for us in relation to this section of the Draft Bill. They are;

- Wording as it affects diversity and quality of information and advice provision that is accessible and personalised
- Advocacy and ability to access independent advice.
- Prevention and the interplay between section 1 and 7

Wording

We have a slight concern about potential unintended consequences flowing from the wording in Section 2(1). Much information provision for carers comes from voluntary sector organisations. Carers will inevitably go to trusted sources of information and advice. This will include the local council but will also extend to carers organisations and advice agencies.

The wording “must establish and maintain” could be seen as restrictive in this context. It may be that this could be clarified in guidance. We would suggest, however, that a more appropriate wording, based on Section 7, would be to say:

“2 [1] A local authority must provide or arrange for the provision and maintenance of services for providing people with accessible information, advice and *advocacy* [see below] relating to care and support for adults and support of carers.

Advocacy

Accessing information and then feeling supported and empowered to use it are closely related. We would suggest that section 2(1) also makes provision for advocacy. This can be a helpful mechanism in enabling carers to exercise their rights and in clarifying responsibilities towards the supported person. Section 8(1) would need to be amended as well to reflect this.

Prevention

In our comments on Section 1 we highlighted the importance of prevention and the ability to reduce the need for care and support. Section 7 makes important provisions in this respect. As constructed Section 2(2) appears to focus on information for accessing systems, services, support and ensuring safety. This is to be welcomed but at the same time we need to ensure this section links strongly to the prevention agenda in our suggested Section 1 and the Draft Bill's Section 7. To ensure this read across we suggest the following addition is considered;

[x] how people can help to prevent needs for care and support from developing or by delaying them and increasing scope for rehabilitation.

Part 1 – Care and Support – Promoting Diversity and quality

This section is about promoting diversity and quality in the provision of services. It reflects a policy commitment towards this that found firm expression within the Department's guidance following the NHS and Community Care Act 1990. There is, however, an underlying supply side sufficiency issue that might be explored further. This may be a matter for guidance.

In relation to carers, we would suggest the reference to "persons wishing to access services" is clarified to make explicit that "persons" includes carers. We recognise this may be a general issue within the Bill and understand it is being looked at.

The other point we would make is that consideration is given to additional provision in section 3(1) (or such other drafting within the Bill) to ensure Section 3 also links with Section 7. For example:

[d] has access to a variety of sources or facilities or resources designed to contribute to preventing or delaying needs for care and support as provided for in Section 7.

Part 1 – Co-operating Generally and in Specific Cases

A consistent message from carers is the need for local authorities and their partners to cooperate in meeting their needs. Section 4(5) lists a range of partners. It also makes provision at 3(5)(g) for regulations to include others. We would suggest two are included:

- Providers of social housing and any regulated provision.
- Voluntary organisations providing information, services or support in the area

We would also suggest that there is a need here for an explicit interplay with requirements for and roles and responsibilities of Health and WellBeing Boards towards adults over 18 and people who are carers.

Similar provision might be appropriate at Section 6 with regard to the promotion of integrated care and support with health services etc..

Part 1 – Section 10 - Assessment of a carer’s need for support

The removal of the requirement to “request an assessment” and for carers to provide “substantial and regular” care is supported. It does raise the issue of demand management where it arises but we see this as a matter for further discussion under the next spending review and for guidance.

The current provisions of the Draft Bill at Section 12 may have the effect of inhibiting the use of self assessment models, validation and approval of assessments. The term “proportionate” is used in section 12 but not Section 10. There is also an issue in relation to the “outcomes being sought” that needs to find expression somewhere in the Bill, regulations and guidance.

Section 10(3) defines a “carer”. There appears to be a drafting omission at this point in that this clause critically omits the words “or support”. As drafted the section would exclude carers who support and encourage people with learning disabilities or with dementia. This needs to be corrected and/or clarified.

This is another part of the Draft Bill where the importance of identifying “impact” on carers is essential. It may be the word “needs” embraces this. It should be more explicit. We would suggest, therefore, that provision is made at 10(4) to cover this as follows:

- [c] what are the impacts of caring and support on the carer in commencing or continuing to provide this

There is also an issue within this sub-section about the need to consider sustainability. That is about not just whether a carer wishes to continue but an assessment of impacts and their ability to do sustain their role. This should include the extent to which care and support plans/arrangements rely on an inappropriate level of caring to make them sustainable. These may be matters for regulation and guidance under Section 12.

Part 1 – Section 11 – Refusal of Assessments

This is a complicated area. We have seen the comments of Carers UK dated July 2012. We do not wish to add to these and agree they need to be clarified.

Part 1 – Section 12 – combined needs assessments

This is a welcome provision. It brings with it a risk, however, that this approach may become a means of demand management. We see this essentially as a matter for guidance. We would still wish to suggest consideration is given to two minor adjustments.

Appendix 1- ADASS Carers Policy Network comments on draft care and support bill.

First, consider amending the wording of 12(3) so that the reference is to an adult needing care *and support* for the reasons given already. Second, as a means of enhancing their involvement, to amend to read “request this and agree” rather than “agree”. The key point is that the entitlement to an assessment is not diminished but gives to people the right to say how it is done in this instance rather than it being “offered” to them.

We also wondered whether more might be done within Section 12 in respect of “*whole family*” approaches, person centred planning and outcomes and so on. These may be matters for regulation and guidance or closer linking to Section 24.

Part 1 – Section 19 – Duty and power to meet a carer’s needs

It would be helpful to clarify in legislation, regulation or guidance where support for carers ends and the services in response to the person needing care and support begin. This is reasonably clear under the Carers and Disabled Children Act 2000 and guidance. It is less clear in the Draft Bill. Carers UK has made detailed comment on this aspect and we support consideration of these points.

Part 1 – Section 31 – Continuity when an adult moves

The provisions for portability of care and the clarification this section seeks to bring are welcomed. This section deals with various provisions concerning ordinary residence and what happens when people move. What does not appear to be covered is the responsibilities of local authorities when the adult with care and support needs lives in one area and the carer lives in another. This is not an uncommon issue in metropolitan areas. We need the same level of clarity .

In 2008 ADASS approved a cross boundary protocol to cover these situations. The Draft Bill seeks to clarify further issues around ordinary residence. It may be the detail is a matter for regulation and guidance. The principles might be covered in a Draft Bill. [Note: the section refers to adult so it may cover carers]

Part 1 – Transition of a child’s needs for care and support and Young Carers

In general we support and welcome the strengthened provisions for transition to adulthood. These are complex.

On transition to adulthood, the Draft Bill is concerned with care and support for adults. This part of the Draft Bill seeks to deal with the transition of children in need to adulthood and young carers into adulthood; although here there is an issue about continuing to care into adulthood. The definition of a “carer” in this section 39(5) is different from that used earlier in the Draft Bill.

Under these provisions a child’s carer must still request an assessment. The rationale for this in the context of the Draft Bill which removes the requirement for adult carers of adults is not clear.

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On young carers, Section 41 of the Draft Bill introduces a new definition of “young carer” which includes a requirement to be a *child in need*. It also requires a young carer [or their parent] to request an assessment. The Draft Bill removes this requirement for adult carers of adults.

The Draft Bill differs from provisions within the 1995 and 2000 Acts, which would appear to continue to remain in force [although it is difficult to work out from the schedules] at the same time alongside provisions within the Children Acts, regulations and guidance which would continue in force.

The definition used at this point appears to exclude young carers who provide care and support for parents with a disability, enduring mental health needs or substance misuse. The reason for this is that the residual provisions of existing legislation for carers would continue to apply.

Whilst understanding why this has arisen, we are concerned that this is a recipe for confused accountabilities and practice. We expressed concern about this in our response to the Law Commission Review. The current situation lies oddly with the cross government approach to carers issues. It sends completely the wrong policy message to young carers and their families. It needs to be resolved through a joined up approach. The draft bill on Children and Families may provide an opportunity to do achieve this. We welcome the willingness of the Department for Education and the Department of Health to listen to our concerns and those of partner organisations. We emphasised the need to complete the legislative review so as to embrace the situation of the thousands of young carers and parents of disabled children. Put simply, the key principles for reform for young carers need to find expression in legislation, regulation or guidance. They should be:

- Consistent with the cross government commitment on carers, the residual carers legislation, which would apply only to young carers and parents of children with disabilities, as proposed should be form part of the repeals process.
- Amendments to the Draft Bills on Care and Support for adults and Children and Families should ensure interplay and integration of legislative, regulatory and guidance frameworks.
- Regulations and guidance in support of legislation should be consistent with and advance the provisions of the ADCS/ADASS/Children’s Society model memorandum of understanding on young carers as follows. This states that:

“a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well being or educational achievement and life chances”

We continue to stress that legislative, regulatory and advice frameworks should ensure Councils focus on meeting the needs of the adult so that children and young people are prevented from undertaking an inappropriate caring role .It should also be expected that Councils focus on preventing and/or reducing inappropriate or excessive caring

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rather than assessing how children and young people need to be sustained or supported in a caring role.

In making these points we are not seeking to stop caring altogether or denying a child's right to be assessed but the child's needs and wellbeing are paramount. We are also clear that children's needs should be differentiated from those of adult carers. As we have framed it, the term "young carer" does not apply to the everyday and occasional help around the home that may often be expected of or given by children in families and is part of community and family cohesion. The key features for us are that:

"caring responsibilities are important and relied upon within the family in maintaining the health, safety or day to day well-being of the person receiving support or care and/or the wider family."

The central issue is one of impact: a point emphasised in relation to adult carers.

We commented earlier on the need for the Draft Care and Support Bill, regulations or guidance to offer a framework. This should provide for:

- A Whole Family Pathway or whole family assessment process, this may be in regulations and guidance (this is already provided for clause 12, but we would like this strengthened)
- Identification of a child who may be caring / where safeguarding issues may arise in a household where the adult has care and support needs
- An adult's eligibility for services to take into account that they are parents and any assessment of a young carer
- Adult's services to adequately meet adult's needs rather than offering a carer's assessment to a child that has the effect of sustaining a caring role
- Provision of services and support to help "sustain a family unit which avoids children being required to take on inappropriate caring roles"

What we need to be able to see in the legal framework is:

- Clear hooks in the primary legislation on whole family assessment and identification of children as guidance may not have the same effect in practice
- Amended transition clauses that encompass all relevant legislation (this is key to why the draft Children and Families Bill needs to be amended at the same time as the draft Care and Support Bill)
- A clear and joined up interface between the adult's and children's legislation to support a whole family approach and enable families, young carers and care professionals to understand responsibilities.

Whilst not within the scope of the Draft Bill, the importance of a cross government approach to legislation, regulation and advice, such as the Framework for Assessment of Need, affecting young carers is underscored by the following:

- Assessment of young carers is patchy, not always focussed on the whole family and can focus too much on the caring role; services put in place are either

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specific young carers projects or under section 17 where there are also safeguarding concerns

- The value of mirrored provision within adult social care and children's legislation for assessing young carers in promoting clarity, joint working and improved outcomes for young carers and their families where:
 - The emphasis is on the child first (rather than the caring role) but who may be at risk of caring which impacts their wellbeing and life chances
 - The approach fits well with the intention of section 17, Children Act 1989 and with emphasis on meeting the needs of the whole family and
 - provides for appropriate identification and support at a lower level than thresholds than may be the case under the Children Acts.
 - Reflects the evidence base, including that of the joint ADASS/ADCS reviews published in 2011/12 on the need to have scope in children's legislation for meeting the needs of children caring for adults with substance misuse issues and mental health.
 - Promotes personalised care and support linked to proportionate assessment and intervention and safety of children.

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19 October 2012