

## Standing Commission on Carers

c/o Department of Health  
Area 116, Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Email : [prussell@ncb.org.uk](mailto:prussell@ncb.org.uk)

October 25 2012

### Response from the Standing Commission on Carers to the consultation on the Draft Care and Support Bill

#### Introduction to the Standing Commission on Carers

The Standing Commission on Carers (SCOC) warmly welcomes the opportunity to contribute to the current consultation on the Draft Care and Support Bill.

The Department of Health established the Standing Commission on Carers in December 2007 at the request of the Prime Minister. The Standing Commission is an independent advisory body, providing expert advice to Ministers and the Carers Strategy Cross-Government Programme Board on progress in delivering the National Carers Strategy (a ten year Strategy published in 2008) and on other policy issues relating to carers and support for their roles. In 2009, the Standing Commission was formally constituted as a Non-Departmental Body, with Chair and members appointed by the Appointments Commission. Dame Philippa Russell has chaired both stages of the Standing Commission's development and current role.

The long-term vision of both the National Carers Strategy and the Standing Commission on Carers' is that:

***'By 2018, carers will be universally recognized and valued as being fundamental to strong families and stable communities. Support will be tailored to meet***

***individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.'***

The last Census (2001) reported that there were 5.67 million carers in Great Britain (around 5.2 million carers in England and Wales and almost 500,000 in Scotland). 58% of carers were women, 42% men. 68% of carers care for up to 19 hours a week, 11% for 11-49 hours and 21% for 50 or more hours. Over-65s account for a third of all those carers providing more than 50 hours a week. 58% of carers are obliged to give up employment because of caring responsibilities. With changing demography and family structures, there is an increase in the number of families with multi-generational (and sometimes distance) caring roles.

Because of the transition of care for people with long-term conditions and for older people from hospital to home and community over the last decade, the Care and Support Bill offers a unique opportunity to create a new legal framework for social care and we are keen to contribute both to the consultative process around the Bill and the subsequent development of, and consultation on, secondary legislation and guidance. .

## Introduction

The Standing Commission on Carers warmly welcomes the publication of the Draft Bill and the extended consultation process (including Pre-Legislative Scrutiny) to ensure that the Bill is as fit for purpose as possible when it goes before Parliament. We particularly welcome the emphasis on well-being and outcomes, thus moving the legal framework for social care beyond the Beveridge concept of a safety net towards a wider and enabling definition of social care which promotes life chances and supports maximum independence and 'ordinary lives' wherever possible.

In particular, we welcome the formal recognition in UK legislation of the principle of *parity of esteem* between carers and those they support. With demographic change and improved medical care, support for carers (and recognition of their own rights and needs as citizens) must be seen as integral to the legal frameworks for both social care and the NHS.

We agree with one group of carers who described the Draft Bill as representing a:

*‘quiet revolution in the way in which carers and disabled and older people are supported by both the public sector and local communities in order to have better lives and to achieve their own potential as equal citizens.’*

We recognize that primary legislation on its own cannot achieve the wide range of outcomes intended by the Bill and hope that there will be an equally full and open engagement with key interest groups once the Bill has Royal Assent and work begins on secondary legislation, regulations and guidance.

We have set out comments out below in chronological order (ie clause by clause) for ease of access. We are of course very happy to provide supplementary information on any points raised, if so required.

## **CLAUSE I: Duty on Local Authorities to promote an adult’s well-being**

We strongly support Clause I, which for the first time lays a general duty on Local Authorities to promote an adult’s well-being. We are particularly pleased that this not only covers physical, mental and emotional well-being but also covers participation in work, education and training and social and economic well-being. We regard the new focus on work and economic-well-being (which goes beyond the original Law Commission proposals) as particularly important, given the impact of caring on many families.

**We have a number of specific points with regard to Clause I, namely:**

- a) We would like clarification at the start of the Draft Bill that the term ‘**adult**’ includes both carers and users of services. Although clarification is given in subsequent clauses, we feel that the ‘parity of esteem’ between carer and user should be set out in Clause I to avoid any possible misinterpretation.
- b) We consider that **Clause 1(2)(f)** with regard to ‘**domestic, family and personal relationships**’ should receive greater emphasis. Good quality care and support must not only meet the needs of the individual concerned but also safeguard and support family relationships and the circumstances within which care and support are delivered. This point could be addressed in guidance.
- c) In **Clause 1(3) (e)** we would like to see reference to the **impact of the illness, disability or condition** rather than a focus on direct involvement in caring.

- d) In the same clause, we would like see an amendment to say '***the importance of achieving a balance between the adult's and young people well-being and that of any friends or relatives....***'
- e) **We would also welcome a specific reference to the carer's own health and well-being and the need to prevent such ill health in the future.** This could be further explored in guidance although we would welcome an acknowledgement on the face of the Bill.

## **CLAUSE 2: Duty on the Local Authority to establish an information and advice service**

We warmly welcome the new duty on Local Authorities to establish information and advice services. High quality information and advice are at the heart of any personalized service and, as our own fact finding visits have demonstrated, many carers find themselves unable to make good decisions or to identify appropriate care and support because they are unable to access the information, advice and advocacy in some cases needed at the time in question.

With regard to this Clause, we have a number of points to make:

- a) **We gather that the provision of information and advice is intended to also include advocacy.** We would like this to be made explicit.
- b) **We would also welcome a reference to brokerage services.** In many cases families will be uncertain about the use of direct payments or personal budgets without assistance in accessing their preferred option and in agreeing the arrangements for its use (and for any financial issues entailed).
- c) **We welcome the inclusion of self funders** (the numbers of which are likely to increase substantially over the next decade).
- d) **We hope that regulations and guidance will specify the range of information and advice services to be offered**
- e) **We note that the Local Authority may delegate the information and advice functions and may also combine with another Local Authority to offer a combined service.** We recognize that many of the best information and advice services currently available are managed through the voluntary sector, eg through Carers Resource Centres or Centres for Independent Living. The delegation of information and advice services to such bodies may well be the

most efficient (and cost-effective) way of empowering both carers and users to make the best decisions about care and support. Hopefully community based information and advice services may also encourage much earlier identification of carers and enable them to access preventive services. However, we hope that regulations and guidance will specify the range of information, advice and advocacy functions expected in the new service to ensure that delegation, if it occurs, is accompanied by sufficient funding to achieve the ends envisaged. We have no doubt about the value in both human and financial terms of good information and advice, but we also note that there are resource implications if a service is to be fit for purpose and sustainable.

- f) **Clause 2(2):** As currently drafted, we note that the focus of the information and advice service appears to be on access to systems, services, support and ensuring safety. These are of course prime areas of concern for carers, but we would also like this section of the Bill strengthened to recognise the importance of prevention. In the spirit both of the Carers Strategy ‘refresh’ and other areas of the Bill, we would welcome an addition along the lines of:

**(x) How people can help to prevent the need for care and support from developing or, by delaying such a need, increase the scope for rehabilitation and the maintenance of maximum independence in the home and local community.’**

- g) **We would welcome clarification as to whether Local Authorities will be able to charge for information and advice services.** We see charging as a potential disincentive to both users and carers and assume that Local Authorities would not normally seek to impose charges for these services. However, we could envisage delegated information and advice services potentially leading to charging if the contract was with a commercial provider.

### **CLAUSE 3: Duty to promote diversity and quality of provision of services**

We welcome the new duty on Local Authorities to promote the efficient and effective operation of a market in services for meeting care and support needs. The spirit of personalisation focuses on choice and control, which must entail a key role for Local Authorities in ‘market shaping’ in order to ensure the availability of a range of high quality services in the area.

We have several points with regard to this duty, namely that:

- a) The duty set out in **Clause 3** is crucial to the effective delivery of the information and advice services required in **Clause 2**. Therefore we hope that the guidance will encourage Local Authorities to be proactive in creating local Market Development Fora in partnership with providers across the public, independent and voluntary sectors and with user and carer interest groups in order to explore and encourage local options for development. We have seen the effectiveness of such Fora in a number of areas and we note that carers themselves are keen to work in partnership with the Local Authority and providers in 'market shaping' for the future.
- b) **With regard to future guidance, we also note that carers (and users) will themselves be micro-commissioners as Local Authorities move towards greatly increased take-up of personal budgets and direct payments.** Therefore we would like encouragement right from the start to include them as key players in developing and promoting an effective and efficient market for care and support at a local level.
- c) **Clause 3(2)(b):** With reference to the requirement for Local Authorities to consider likely future demand for services, we would welcome encouragement to use the JSNA as a means of measuring both current supply against demand and anticipating likely future patterns of demand for care and support.
- d) **Clause 3(2) (d):** In this context, we would have welcomed a requirement analogous to that set out in the **Childcare Act 2006** and the **Social Care (Local Sufficiency of Supply) and Identification of Carers Bill** to encourage Local Authorities to not only develop a local market but also to monitor the match between supply and demand and thereby to also seek continuous improvement in quality and availability.
- e) The requirements set out in the Childcare Act 2006 have been widely regarded as fair and effective and have certainly improved the range and availability of care for parents of disabled children. We hope that guidance will encourage prospective approaches to market shaping and development.

## **CLAUSE 6: Promoting integration of care and support with health services etc**

- a) **We welcome this clause, given the inter-dependence of health and social care for ensuring good outcomes for both users and carers in most cases.** We would welcome cross-referencing to relevant NHS legislation and guidance,

noting the emphasis on integration within the NHS Constitution and Draft NHS Mandate.

- b) **However, we are unclear as to where the reciprocal duty to cooperate will lie with regard to the relevant *health* bodies.** Clearly the Health and Well Being Boards and Healthwatch will have key strategic roles in encouraging cooperation between health and social care. However, effective integration will also necessitate proactive relationships with the local Clinical Commissioning Groups, the relevant NHS Trusts and in some cases with the NHS Commissioning Board itself.
- c) **We would welcome a reference to the proposed introduction of Personal health Budgets** (expected by 2014) in the guidance if not on the face of the Bill, because their wider usage will raise the profile of integrated health and social care services at local as well as at national level.
- d) **With regard to integrated care and support plans, we note that the Education, Health and Care Plans introduced in the Children and Families Bill will cover young people up to the age of 25.** We suggest that guidance might encourage their use as a model for integrated planning arrangements for future adult care.

## **CLAUSE 7: Preventing needs for care and support**

We warmly welcome a formal recognition of the importance of prevention on the face of the Bill, with a new duty on the Local Authority to provide or arrange for services, facilities or resources which will prevent or delay the development of (or reduce the needs) of care and support for adults.

As noted earlier, we recognize that the term ‘adults’ is intended to include carers whenever it is used throughout the Draft Bill. However, to avoid confusion, we would still welcome a specific reference to carers here to avoid confusion.

## **CLAUSES 8 – 10: Assessment and how to meet needs**

**Clauses 8 and 9:** We welcome the focus on outcomes in Clauses 8 and 9 and the need to consider whether any care or support provided will assist in achieving these specified outcomes. We particularly welcome:

- a) **The removal of the requirement for the carer to request an assessment and:**
- b) **The removal of the requirement for the carer to be providing substantial and regular care.**

However, we have several comments to make: We note that **Clause 8(1)** sets out a number of examples of what may be provided to meet assessed needs. We recognize that this list is not intended to be comprehensive, but will no doubt be further developed in guidance. However, we suggest that transport (often key to personalized options for care and support) and equipment should be added in guidance if not on the face of the Bill.

**Clause 9 and assessment:** With regard to Clause 9, we note that the term ‘*assessment*’ is often widely interpreted and, in some cases, is little more than a short conversation. Although we recognize that some assessments will be shorter or indeed more focused than others, we are concerned that assessments should be appropriate to individual and family needs and robust enough to ensure good outcomes. We note the *Penfold Judgement* (R v. Bristol ex parte Penfold, 1997-8). The *Penfold* case established the principle that an assessment must properly consider all of the individual’s needs, with the Court holding that ‘***assessment cannot be said to have been carried out unless the local authority has fully explored the need in relation to the services it has the power to supply. In some cases this exercise will be simple, in others more complex.***’

If, as is possible, a Local Authority decides to delegate some of its assessment functions, then we hope that regulation and guidance will ensure that any assessments must give proper and proportionate consideration of the individual or family in question and the assessor should be suitably qualified and experienced.

With regard to **Clause 9**, we also note:

- a) **Clause 9:** This Clause states that where it appears to the Local Authority that an adult may have needs for care and support, then the authority must assess. The duty of the Local Authority towards an adult who may have needs for care and support is mirrored in a similar duty in **Clause 10(1)** towards carers. In many cases it will be the carer (or possibly a professional in the NHS) who first identifies a need for care and support and we would welcome a reference in each Clause to the Local Authority’s need to ***consider*** to any concerns about the need for care and support. Such consideration would not seem to be unduly burdensome as the Local Authority will determine in an assessment what, if any, needs exist and how they might be responded to.



- b) **Clause 9:** We consider that there should be a requirement on the Local Authority within this Clause to engage with health or other professionals as appropriate in order to determine if an individual has a need and how it might be met.
- c) **Clause 9(5):** We suggest that carers should also be '*informed and engaged*' rather than only '**consulted**'. We are aware that some young carers will not necessarily be actively engaged in their relative's assessment and any treatment or support programme. However, we hope that all carers, of any age, will be consulted and informed and *appropriately* engaged to ensure that they full understand the nature and level of care required of them.
- d) **Clause 10 (5):** We are pleased to see a requirement that the Local Authority (when carrying out a carer's assessment) must have regard to whether the carer works or wishes to do so or whether the carer is participating in (or wishes to participate in) education, training or recreation. This is a welcome and over-due recognition of the changing nature of family care, with the majority of carers of working age expecting and needing to continue in paid employment.
- e) **Clause 10(3)** defines a carer but does not make reference to '**support**'. Many carers of young adults (eg with a learning disability) provide considerable emotional and practical *support* as a key element in their caring roles, although they may not provide '*hands-on*' physical care.
- f) **Clause 10 (5):** We would also welcome a reference to *unpaid work or community activities* in this context. With an emphasis in public policy on developing community capacity in supporting vulnerable people without the need for formal support, more citizens are providing regular and sometimes substantial voluntary contributions to their local communities. In particular, many older people may be providing substantial support and unpaid care through childcare for grandchildren or other relatives or through community groups and networks. In many cases these multiple *unremunerated* roles will also have a preventive factor in contributing to their own physical and mental health well-being.
- g) **Clause 10(6): Understanding the impact of caring:** We welcome the requirement in 10(6) that the Local Authority should so far as is feasible not only consult the carer but also any person whom the carer asks the Local Authority to consult. We consider this particularly important in the context of **Clause 10(4)** when the carers' assessment should include an assessment of whether the carer is able and will continue to be able to provide care and whether they are *willing and will continue to be willing to do so*. With a new focus on well-being and outcomes throughout the Bill, this requirement is particularly important because of

the long-term nature of many caring roles and the implications for wider family members. We note the implications of the improved life expectancy of people with learning disabilities and we hope that guidance will consider this sub-section with regard to succession planning for older carers and also planning for a time when a carer's own health or disability may preclude continuing care at its present level.

h) Within this **Clause 10**, we would like to see a specific reference to **'the impact on the carer of both commencing and continuing to provide care and support.'** We see the acknowledgement of the potential impact of caring as crucial both in any initial assessment when the carer assumes a caring role and also with regard to the sustainability of this role. We note that many carers now provide care and support over decades because of improvements in medical care.

i) **In Clause 10(7 and 8), reference is made to the circumstances in which a carer is not to be regarded as such in the context of the Care and Support Bill.** We are aware of ongoing discussions over a number of years as to an acceptable legal definition of a carer. There is often widespread confusion (including amongst carers themselves) about the distinction between a paid carer (ie a paid care worker) and a family carer. We note in Clause **10(8)** that a Local Authority may in certain circumstances decide to ignore **10(7)** and determine that the person providing care is in fact a carer despite presumably receiving some financial reimbursement for that role. We assume that the circumstances referred to might include a disabled person receiving a personal budget who used some of that budget to address the costs incurred by a family member or friend supporting him.

We are aware that personal budgets in the UK (unlike their equivalents in other Western European countries) do not usually permit cash payments to relatives in lieu of payment to a formally employed care worker. However, we are also aware of certain circumstances when it would be very desirable to reimburse a family member (eg when language or other issues are paramount) or when there are significant losses of earnings by a non-resident relative for providing particular aspects of care and support. Therefore, we would be grateful for further clarification of 10(7 and 8) in regulations and guidance.

j) **With regard to Clause 10(7), we would also welcome clarification in guidance about the interpretation of a carer providing support through 'voluntary work'.** Many disabled and older people and carers make small payments (often as donations, sometimes to cover costs such as transport) to volunteers who provide some care and support. Whilst these '*occasional*' carers clearly would not be eligible for a carer's assessment, the flexible use of a direct

payment or personal budget to defray immediate expenses etc incurred on behalf of a volunteer could be an important element in an early prevention strategy. We refer to personal budgets elsewhere in this submission, but we would welcome clarification in the secondary legislation and guidance as to what direct payments/personal budgets may be used for.

## **CLAUSE 11: refusal of assessments**

Adults needing care can refuse assessments and we recognize that the Local Authority is under no obligation to carry out an assessment unless the adult in question lacks capacity or is at risk of abuse, neglect or harm. Carers can similarly refuse an assessment and the Local Authority is not obliged to carry out such an assessment unless it has particular concerns about a change in circumstances or there are safeguarding issues. We consider that this Clause should be further explored in guidance. A carer may refuse an assessment because he or she is anxious or misinformed about the possible outcomes. Therefore, we hope that:

- a) **Guidance should encourage Local Authorities to provide information (with access to advice and advocacy if required) alongside any offer of an assessment.** It is unlikely that an elderly person, unaware of the possibilities of personal budgets or domiciliary care, will be enthusiastic about a much needed assessment if they perceive the only outcome as the removal of a partner to a care home. If assessments are to move from crisis interventions to more proactive and preventive assessments (with a corresponding reduction in more expensive interventions because of family stress or breakdown), then it is important that assessments are 'marketed' as proactive, positive and (in the case of self-funders) seen as separate to paid-for care or support. We realize this is an issue for guidance rather than primary legislation, but wish to underline the importance of understanding the frequent anxieties behind reluctance to undergo assessment and the importance of good information and advice services in unblocking such resistance.
- b) **Clause 11(7):** In certain circumstances, a refusal to agree to an assessment (on the part of either the person needing support or the carer, or sometimes both) may leave both at considerable risk of neglect, abuse or harm. We see this as an issue for both the Local Authority and the local Adult Safeguarding Boards to consider. If either the person needing support or the carer is at risk, then refusals to undergo assessment must be over-ridden.

## CLAUSE 12 – Assessments under 9/10 – further provision

We warmly welcome the new requirement that a Local Authority should have regard to the needs of the whole family around the person for whom an assessment is being carried out.

- a) **Clause 12(3): We also warmly welcome the proposed new ability of a Local Authority to integrate an assessment of both the person needing care and support and the carer.** We recognise that both parties must agree to this proposal, but are convinced that it will greatly assist many families and improve the well-being of carers in particular. Because of demographic change and the rise in distance caring, many people needing care and support (in particular older people) may receive care from several carers, often living at some distance.

In many European countries, family conferencing arrangements have been developing to take account of the greater complexity of 21st century families and the importance of mutual understanding about reciprocal roles and responsibilities. We also note the *Whanau* system used in New Zealand when multiple family members may need to be involved in assessment and care planning. We are aware that these issues need exploration in secondary legislation and guidance, but flag them up now because of their importance in a major development in assessment for care and support.

- b) **Clause 12(3):** We would like to see ‘**and support**’ added to the reference to needing care, for reasons noted in our comments on **Clause 10(3)**.
- c) **Clause 12 (4 and 5):** Clause 12 suggests that the Local Authority may delegate responsibility for assessment to another body or carry out an assessment jointly with a partner. Whilst we are aware of some Local Authorities have already delegated initial assessments to a trusted voluntary sector partner (eg a Carers’ Centre or similar organisation), we would welcome clarification as to the conditions for so doing. We can envisage the advantages of partnership approaches to assessment in a number of cases (eg in partnership with the NHS or with a trusted voluntary sector organization with relevant experience and expertise). However, we are concerned at the possibility of out-sourcing to a commercial or other body without adequate safeguards.
- d) **Clause 12 (4 and 5):** If assessments are out-sourced, we are unclear as to how disputes or complaints might be managed. We would welcome clarification as to where the *legal* responsibility for the assessment will rest and how carers (or users) might challenge any aspect of that assessment with which they had concerns. We have also heard concern expressed about the exchange of

confidential information with a third party, with some carers asking if they could express a preference for the Local Authority itself if they did not wish to share information with a third party.

### **Clause 13: Eligibility Criteria**

We welcome the proposal that there should be a national eligibility framework for social care and support. The 'post code lottery' has presented continuous problems for carers, users and in many cases local authorities themselves because of widely varying interpretations of 'need'. We note from the White Paper that it is likely that the threshold for eligibility will be set at 'substantial'. Therefore, there will be a wide range of needs not necessarily set at 'substantial' but capable of escalating to a higher level without support.

We recognize that there will be formal consultation on the proposed eligibility framework, but refer back to **Clause 7** (Preventing needs for care and support) and hope that the forthcoming guidance will explore options for adopting a stronger preventive approach towards needs for care and support and encouraging the early intervention which may remove the requirement for more substantial investment in support in the future.

### **Clause 14: Power of the Local Authority to impose charges**

We recognize that Local Authorities will charge for some services provided, but have some concerns about the title of this clause. We would prefer to see '*impose*' replaced by something like '*Local Authority charges for services*'. Many disabled people (and carers) are frightened of suddenly incurring costs for care and the use of the term '*impose*' does not reflect the intention of a better informed and negotiated assessment system, with both sides understanding both entitlement and responsibilities. Additionally not all Local Authorities charge for all services, having a *power* but not an absolute duty to do so.

With regard to this Clause, we also note that:

- a) **Clause 14(I)**: We will need clarification about the new powers of Local Authorities to charge not only for the actual services which they may provide for non-eligible needs or for people who are above the financial limit for local authority help but for putting in place the arrangements for such needs.

Historically charges have only been made for a service provided and not for the management or arrangement charges for putting the service in place.

- b) **Clause 14(5):** We are pleased that regulations will specify an amount below which an adult's income must not fall after deduction of a charge is made. We hope that regulations will also take account of the implications of loss of earnings for a carer if required to provide an excessive amount of care and that there will be clear criteria for establishing what charges (eg mortgage repayments, costs of childcare for dependent children, transport etc) can be set against an adult's income before charges are made.
- c) **The basis for calculating charges:** We gather that regulations will be introduced which will offer protocols for calculating income, capital, exemptions etc. with regard to local charging policies. Currently different rules regarding charging apply to residential and non-residential care. We hope that these will be clarified.

We note the importance of this Clause in terms of the protection it offers to carers from being charged for services which are essentially those required by the adult needing care and support. Under **Clause 14(3)**, if the Local Authority considers that the *carer's* needs are best served by providing more services to the adult needing care, then it is the *adult* who should be charged. However, we consider that it will be important to clarify in guidance and regulations how best to determine whether a service is a service to the carer or to the person needing care and support and also to consider how carers may be best supported when their relative refuses the services offered or is unwilling to pay charges incurred in using them.

## CLAUSE 16 – Deferred Payments

**We welcome in principle the requirement that Local Authorities should have both a duty and a power to operate a deferred payment system.** Local authorities can already defer taking a charge on a property when a person enters residential care (although this option is not widely known and few Local Authorities publicise the option). However, we note that the proposal in the Bill is that Local Authorities can now charge interest on the deferred payments, charge for any administration costs and also charge interest if necessary on those costs.

**We are concerned that the system could incur considerable costs for some families and (without some checks on the amounts of interest charge) could replicate the current problems with equity release schemes.** We would welcome

clarification on the likely charges being made and suggest that the information and advice services introduced in **Clause 2** should not only include written information but also access to financial advice on the implications of deferred payments.

### **CLAUSE 17: Duty to meet needs for care and support for adults needing care**

We welcome the duty to meet needs within eligibility criteria, following an assessment of needs and if applicable a financial assessment. However, we would welcome also clarification of **Clause 17 (1 and 2)**. It has been suggested that this Clause removes the current absolute duty of a Local Authority to meet needs regardless of resources (but of course with the proviso that they can impose charges and recover through the Courts if necessary). The current drafting suggests that the new duty applies to applicants meeting the financial criteria albeit with the power to meet the needs of others whose financial resources exceed the current eligibility limits and for whom charges would be made.

### **CLAUSE 19: The duty and power to meet a carer's need for support**

We welcome **Clause 19(8)** for its recognition that if a carer's need for support cannot be met by providing care and support to the adult needing care, then the Local Authority must identify some other way of providing that support. However, we have some concern that:

- a) We note that there is currently very little clarity about where carers' services end and where services for the person needing care begin.
- b) We cite the **Carers and Disabled Children Act 2000**, where a very clear distinction is made between the two sets of needs.
- c) In **Clause 19(3)**, the current drafting implies that the Local Authority will pay if the carer asks it to meet the identified needs even after the carers' financial resources are judged to be above the limit. This Clause should say '*the carer nonetheless asks the authority to **plan** the needs in question.*' We note the widespread concern that self-funders should not be excluded from support with assessment and care planning, even if they are not eligible for any financial support.
- d) **Clause 19(6)**, as elsewhere in the Bill, makes reference to the consent of the adult needing care and support when support to that adult is the best way of

helping the carer. Whilst we accept that a duty to accept care and support to relieve a carer cannot be enforced on the individual concerned, we would like to see a reference within the Bill to the need for the Local Authority to offer information, advice and support to both carer and the person needing care and support where it is clear that some form of mediation or dispute resolution is needed. We are not suggesting recourse to formal mediation procedures, but note the importance of supporting families before breakdown. We also note the overarching principle of well-being within the Bill which should ensure parity of regard for both carer and the person needing care and support.

- e) **Clause 19(6):** With more carers supporting relatives or friends with serious mental or physical health problems in the community, it is vital the carer's own health and well-being are protected. If a refusal to accept care and support means a carer having to carry out physical lifting and moving which is prejudicial to her or his own health or if the behavior of the person needing support is particularly challenging and the carer put at risk, then a refusal to accept care and support must be seen as a safeguarding issue. We hope that guidance relating to the new safeguarding duties will further address this issue.

## **CLAUSES 23-24: Steps for the local authority to take: the Care and Support Plan**

We welcome the introduction of the Care and Support and the Care Plans. Some specific points include:

- a) **Clause 23:** We suggest saying '**adult and carer**' as the Local Authority will presumably have to inform the carer as well as any adult needing care and support if they decide to prepare a care and support plan/a support plan. We would hope that the Local Authority would inform the carer as well as the adult of any needs that were going to be met (**Clause 23(1)(b)**) and similarly help the carer as well as the adult with deciding how to have those needs met (**Clause 23(1)(c)**). Whilst we have been assured that '**adult**' can also include '**carer**', we feel it would be helpful for a wider readership to repeat carer wherever appropriate.
- b) **Clause 24(11):** We welcome the reiteration that the Local Authority may combine a Care and Support Plan with a Support Plan if both the carer and the user agree.



- c) **Clause 24 (7):** We would welcome a cross reference to **Clause 2** and the provision of information, advice and advocacy to carers and users of care and support services. As a general point, we hope that guidance will in due course provide more detailed information on the development and content of the Care and Support and the Support Plans and offer further information on the reference in **Clause 24(7C)** to *'whatever resources, or access to whatever facilities the authorities think are required to prepare the plan.'*
- d) **A general comment: measuring the impact of care and support on family members:** Family carers have regularly told the Standing Commission on Carers that they are keen to carry on caring for their relative, but want the impact of such caring acknowledged in any assessment or care planning arrangements. This is particularly important when the views of the user (who may in fact refuse any external care and support) and the carer differ. We welcome the formal recognition of personal budgets as key to future care planning arrangements but also note the anxiety amongst many families about what they anticipate will be an extra burden of care (both around managing the audit trail for the budget and also procuring appropriate help). We hope that the advent of *personalized* information and advice services (**Clause 2**) may assist but also suggest that reviews of any support plans should include a reference to the impact on the family and their ability to continue with the same level of support.
- e) **Clause 27:** We would welcome clarification as to definitions of **'accommodation'** and assume that these will be offered in regulations and guidance. Concerns have been expressed that **'accommodation'** in the context of this Clause refers specifically to care homes. We hope that the Bill will acknowledge the diversity of accommodation options (from support in the family home, through supported or extra care housing to care homes) and that the guidance will acknowledge the importance of good quality advice on housing options and related financial arrangements to avoid premature and expensive relocation of a person needing care and support to a residential setting.
- f) **Clause 27: Choice of accommodation for younger people:** With regard to this section, we have particular concerns about young disabled people or young carers, for whom a *'home of your own'* is likely to be the desired step on a pathway to maximum independence. We are aware of considerable anxiety amongst both families and young people themselves about the risk of inappropriate placements (often in care homes for older people) because of the lack of forward planning for a more independent future. We would like to see a preference sought and expressed in assessments right from the start in order to permit forward planning and to enable the Local Authority to plan towards such

provision. We are aware that this may be a matter for guidance rather than primary legislation but are concerned that the issue of preferred accommodation for younger people should be seen as a key issue in planning care and support.

## CLAUSE 25: Personal Budgets and CLAUSES 28 and 29: Direct payments

We are pleased to see a legal definition of personal budgets. However, we hope that this clause will be greatly amplified in subsequent secondary legislation and guidance.

- a) **Clause 25: Integrated assessments and personal budgets:** A personal budget must of course include a financial statement but it should also demonstrate more creative ways of meeting assessed needs. **Clause 25(2)** makes reference to the possibility of including funding from housing, the NHS etc. within an integrated budget and we would welcome a stronger reference to integrated assessments within the Bill.
- b) **Clauses 25, 28 and 29: Information and advice:** We note the importance of *personalised* and individually tailored information and advice services to ensure that carers feel confident and are able to make the best choices. Drawing on evidence from the Carers Strategy Demonstration Sites and the Standing Commission's own recent fact finding visits, it is very clear that that carers can often find good (and cost-effective) solutions to their own caring needs if they are supported in having an open and informed discussion regarding their own and their relatives's care and support plans. Therefore we hope that a robust assessment arrangement will be seen as integral to the further development of personal budgets.
- c) **Clause 25: Querying a personal budget:** We are unclear as to how a carer might appeal against the level or content of a personal budget. Whilst all Local Authorities must have complaints procedures in place, many carers tell us that they would rather '*raise concerns and have a full and frank discussion about the issues worrying them*' with a view to reconciling differences without recourse to formal procedures. The current drafting does not reflect the spirit of co-production which is demonstrated elsewhere in the Bill.
- d) **Clause 25: Clarification of management arrangements for a personal budget:** Many carers (and users) are still unaware that a personal budget does not have to be taken as a direct payment but can be managed in a number of different ways to minimize the potential burden on carers who are reluctant or

unable to manage the budget themselves. We hope that guidance will ensure that carers and users are given clear information about options and about the support they might expect, should they decide to manage a personal budget themselves.

- e) **Clause 29 and mental incapacity:** We are pleased to see clarification about the use of direct payments on behalf of a person who lacks mental capacity. We are aware of a number of cases where the carers of people with dementia, who would have benefited from the flexibility of a direct payment, were unable to access a direct payment because of uncertainty about their status. We hope that the Bill or related guidance will also clarify that a direct payment can be made to a nominated organization as well as to an individual carer.
- f) **Clause 29: Use of direct payments:** We would also welcome clarification as to whether the direct payment, which may form part of a personal budget, can be used in certain circumstances to pay another family member. We hope that this can be clarified in guidance and regulations.

## **CLAUSE 26: Review of care and support plan or support plan**

As noted elsewhere, we welcome the emphasis within the Care and Support and Support Plans on outcomes and the overall well-being of user and carer. We hope that guidance will encourage a proactive approach to review, not only in terms of the returns on the financial investment in care and support but most importantly on the outcomes for the carer and user.

Many caring situations will change. In the case of a person recovering from stroke or trauma, improvements and greater independence will hopefully occur over time. But in many instances, for example when the person cared for has dementia or a degenerative condition, there will be no improvement and the family's needs may increase considerably. We also note the large number of families who are in effect '*life-long carers*' for adult children with a learning or other disability. In these cases, the ability of the family carers may change over time and they may be less able to offer the same levels of care and support. We also note the growing number of '*mutual carers*', for example an ageing parent with an adult son with a learning disability.

- a) **A review should identify and anticipate any changing needs** (which may not necessarily be best met by the local authority, eg more could be more

appropriately met through housing or health services provision such as adaptations, telehealth etc.)

- b) **We hope that guidance will encourage a review process which will not only discuss what has been provided over the *previous year* but will also provide some *prospective long-term planning information***, eg because of an ageing carer or because of the likelihood of more intensive caring over time.
- c) **It is important to understand that carers not only provide direct care but also provide high levels of support.** This support (which may be emotional as well as physical) may entail considerable levels of supervision, accompanying the person needing care and support to medical and other appointments; calling round regularly to check that all is well. Support may mean carers being '*on call*' and unable to be work reliably or to care for other members of the family as they would wish. It may also involve considerable travel time if the recipient of care lives in another Local Authority, with many carers referring to their exhaustion as they endeavour to support a relative at a distance. In this context, we reiterate a point made elsewhere in this response, namely the importance of measuring the *impact* of caring on the individual carer and family. Good reviews, like the plans that precede them, need planning based on good information and, as noted above, we hope that the forthcoming guidance will give due attention to their conduct.
- d) **We refer back to the duties in Clause 2 with regard to information and advice.** We suggest that users and carers should be encouraged to use the local voluntary sector to prepare both for their plan and for subsequent reviews. With regard to the outcome focus across the assessment and care planning process, we also note that independent advocacy, support and brokerage can benefit the Local Authority. Many carers assume their caring role after a crisis (eg a stroke) and are not necessarily thinking longer term about options for themselves or their family member. Independent information, advice and support can encourage and support whole families to make better decisions and maximize independence. Such support will also help encourage take-up of personal budgets and direct payments and help avoid precipitate and expensive recourse to residential care.
- e) **Self funders and reviews:** We would also welcome assurances that reviews of care and support plans should be available to self funders. We are unclear as to whether a Local Authority would have the powers to charge for assessment and care planning (and review) for self funders but hope that these core services would remain free of charge, albeit carers or those they support being charged for actual services provided following financial assessment.

## CLAUSES 31-33: Portability

There is general welcome for the introduction of new arrangements to ensure portability. However a number of concerns have been raised, including:

- a) **Compatibility between provision for social care and support and portability of NHS provision**, including Continuing Health Care.
- b) **Transitional arrangements**: We are unclear if there will be a time limit on transitional arrangements whilst the new arrangements are put in place.
- c) **Transitional arrangements for young people**: We note that young people covered by the provisions of the Children and Families Bill will remain the responsibility of their local authority and local children's services up to the age of 25. Concerns have been expressed about situations where a young disabled person may move out of area for residential college or other education or training and wish to remain in that Local Authority on completion of his or her course. Local Authorities must now continue provision beyond 18 whilst arrangements are made for the young person to move to adult services. However, some families are expressing considerable concern as to the appropriateness of some children's/young people's services for young adults and the risk of the young person being left in limbo whilst the new authority agrees provision. We would welcome clarification of the respective responsibilities of the former and the new authorities during the transition.

## CLAUSES 34-38: Safeguarding adults at risk of abuse of neglect

- a) **Clause 34**: We welcome the strengthening of safeguarding duties for vulnerable adults and the duty for local authorities to make enquiries and take action if required should there be concerns about risk.
- b) **Clause 34**: We welcome the inclusion of financial abuse within the categories of risk, neglect or abuse which the Local Authority may wish to investigate.
- c) **Clause 35**: We have welcomed the requirement for all Local Authorities to have Safeguarding Adults Boards and hope that there will be guidance as to the membership of such Boards in order to ensure maximum effectiveness. We hope that the Boards will be actively encouraged to engage with the local

community of carers and users to ensure early warnings of any concerns about safeguarding in the area.

- d) **Clause 35:** We note that Safeguarding Adults Boards are required to publish a strategy and an annual report and hope that they will be required to demonstrate that they have engaged their local communities in this process. We note that historically carers' and users' concerns about hate crime and abuse in community settings have not always had the response that should be expected. Therefore, we hope that they can contribute to the effectiveness of the new Boards by working in partnership with Board members both to identify problems and to find local solutions. We suggest that guidance might address this point.
- e) **Clause 35:** We would like to see reference within regulations and guidance for Safeguarding Adults Boards to engage with the relevant Health and Well-Being Boards in order to identify relevant areas of concern and to ensure that strategies and planning arrangements fully reflect local needs. Although there are already assumptions that the Boards will engage with Healthwatch, we are unsure if this would be sufficient to ensure that *carers'* particular concerns would be heard and acted upon in the context of other local priorities. JSNAs and Health and Well being Boards have an important role to play in local safeguarding arrangements for the whole community.
- f) **Clause 35:** We would like too see a reference to safeguarding of *carers'* own interests. Many carers express concern at the difficulty often experienced in raising concerns about their personal safety and the lack of support to address their concerns. We note particular concerns about some young carers' well-being, but carers' safety is an issue across the age range.
- g) **Clause 38:** We welcome the requirement on Local Authorities to protect the property of adults cared for away from home.

### **CLAUSE 39 and 40: Assessment of a child's need for care and support.**

**Clause 39:** We are concerned that there appears to be a different test for triggering an assessment of a child's or a parent's need for care and support as compared to the assessment of an adult. In the case of the former, the assessment must be requested, whereas in the case of adults and adult carers, the local authority has a duty to consider assessment when it considers that there might be a need. We are aware that this issue arises because of the transition process between children's and adults' legislation and

feel that the *appearance* of the likely need for care and support should be an adequate trigger in both cases.

We also note that there appear to be two definitions of who is a carer, ie ‘a new definition of a carer which *‘in relation to a child in need, means a person, other than a parent, who is providing care for the child whether or not under or by virtue of a contract or as voluntary work.’* We would welcome clarification.

### **Clause 43: continuity of services under Section 17 of the Children Act 1989**

We welcome the intention to ensure continuity between children’s and adult services for young disabled people. However, we are unclear as to the length of time for which a Local Authority might be able to continue making provision for young people after the age of 18. The **Children and Families Bill** offers continuity up to 25, but many young people would not wish to continue receiving a service designed for a child well into their early adult life. We hope that **Clause 43** can set clear parameters not only for continued delivery of children’s services until adult provision has been agreed, but also for joint working between adult and children’s services to ensure a planned transition.

### **CLAUSE 41: Assessment of a young carer’s need for support**

We have concerns that a young carer or his or her parent has to request an assessment, whereas under **Clause 9** of the Bill, the local authority has a duty to assess adults if they consider that the carer or user may have needs.

- a) We note that there is also an additional and higher test for young carers and their parents inasmuch as the young carer or a member of his or her family must be receiving services under **Section 17 of the Children Act 1989**. Many young carers will not be receiving services under Section 17 of the Children Act but will be supporting parents whose care and support, if any, will be provided under current adult social care legislation, eg the **Chronically Sick and Disabled Persons Act**.
- b) **Clause 41 (8 and 9)**: We welcome the expectation that the young carer’s assessment must include whether the young carer is able and willing to continue caring and also the requirement that any assessment must have regard as to whether the young carer works or wishes to work or is participating in (or wishes to participate in) education, training or recreation. These requirements, analogous to the duties in adult carer assessments, should encourage more

proactive planning in recognition of the importance of ensuring good outcomes as the young carer moves into adult life.

- c) **Supporting the whole family:** We note that the ACDS, ADASS and Children's Society Memorandum of Understanding (***Working together to support young carers and their families: a template for a local memorandum of understanding between Statutory Directors for Children's Services and Adult Services***) is clear that identification of inappropriate caring by young carers is a matter for assessment, which in turn makes the current higher test for assessment for young carers problematic. The same Memorandum of Understanding acknowledges the importance of ***whole family assessment*** and support for young carers to enable the family to function well. In line with the Government's emphasis on prevention within the Care and Support Bill, we hope that the current complex legal framework and inconsistencies for young carers can be clarified and that guidance will further develop the concept of whole family assessment and engagement in the best interests of young carers..

## In conclusion

The Standing Commission on Carers hopes that it can work with the Government and the Department of Health in ensuring that the Draft Care and Support Bill and its related secondary guidance and regulations can fulfill the ambitions set out in the White Paper and achieve a framework for a social care system which is indeed fit for the 21st Century and whilst at last provides parity of esteem both for carers and for those they support.

**Dame Philippa Russell,**

**Chair,**

**Standing Commission on Carers,**

**E-mail: [prussell@ncb.org.uk](mailto:prussell@ncb.org.uk)**

**[scoc@dh.gsi.gov.uk](mailto:scoc@dh.gsi.gov.uk)**



