

Standing Commission on Carers

c/o Department of Health
Area 3, Richmond House
Whitehall,
London SW1
Email : prussell@ncb.org.uk

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Response from the Standing Commission on Carers to the consultation on the Pre-Legislative Scrutiny of 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 Pre-Legislative Scrutiny stage of 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 refreshed in 2010) 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 Census (2011) suggests that there are approximately 6 million carers in Great Britain (around 5.2 million carers in England and Wales and almost 500,000 in Scotland). 58% of carers are 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 a corresponding number reporting a range of health problems relating to their caring roles. Increasingly carers are themselves micro-commissioners of services (via personal budgets or as self funders) as well as direct providers. With changing demography and family structures, there is an increase in the number of families with multi-generational (and sometimes distance) caring roles.

The contribution of carers is vital to the delivery of both health and social care and to the wider economy and the Standing Commission on Carers warmly welcomes the Draft Care and Support Bill, with its welcome emphasis on parity of esteem between carers and those they support. We recognize that the Care and Support Bill offers a unique opportunity to ensure that modern social care and support are fit for 21st century ambitions and lifestyles. We also acknowledge the challenges inherent in developing a system of social care and support which sets out both entitlements and mutual responsibilities and is in effect co-produced with local citizens and their communities. The Standing Commission on Carers is keen to make a constructive and ongoing contribution to this agenda of change and to the achievement of the ambitions within both NHS and social care reform for high quality services which maximize independence and achieve the best possible outcomes for both users and carers.

We have responded to the key questions posed by the Joint Committee below.

Introduction: Part One of the Bill – Care and Support

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 English 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 and valued 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 for ease of access. We are of course very happy to provide supplementary information on any points raised, if so required.

Question 4: 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 increasingly long-term impact of caring on many families.

We are aware that there are limits on the extent to which well-being can be explored and interpreted on the face of the Bill and hope that it can be further discussed in guidance in the context of well-being and quality of life not only of the person needing care and support but also of the family members or friends contributing to that care and support..

However, we have a number of specific points with regard to Clause I, namely:

- a) We would welcome 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 at the beginning of the Bill, in Clause 1, to avoid any possible misinterpretation of the use of the term ‘adult’.
- 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 (and further explored) 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. We note that some illnesses, disabilities or conditions may have very different implications for the families of those affected and for the level and complexity of their caring roles.
- 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 a strong acknowledgement on the face of the Bill.

Question 6 and 24: Benefits and problems of Bill’s focus on adult carers – and transition from children’s care and support services and young carers.

We recognize that children and young people will need different levels of care and support and related safeguarding arrangements as compared to adults. However, we are also very aware of the importance of ensuring smooth transitions between adult and children’s services (for example when a parent carer of a disabled child becomes the carer of a disabled adult) and in the management of situations as with young carers when adults and children or young people are both affected within a single caring situation.

We set out some of our concerns below:

- a) **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.
- a) We also 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) **Although the draft Care and Support Bill is concerned about *adult* social care, with the Children and Families Bill considering issues relating to young carers and parent carers, we would hope that there could be clarity and consistency across both pieces of legislation with regard to definitions of who is a carer.** We note that the Children and Families Bill also uses the term 'carer' to apply to people with caring roles who are not the parent of the child or young person in question.

'[a carer] 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.'

However, in adult social care, the term 'carer' defines someone (not necessarily a relative) who is providing *unpaid* care and support to another person. Many families (and members of the wider community) are confused by the term 'carer', which is frequently confused with 'care worker'. We hope that guidance will clarify definitions (we note that many parent carers and young carers will move on to caring roles in adult life. Therefore definitions in terms of potential care and support needs are also important).

- c) **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.

- b) **Clause 42 (8 and 9): Raising expectations about the life-chances of young carers:** 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.

In this context, we hope that the focus of an assessment of a *young carer* will be similarly outcome-focused to that of an assessment of an *adult*. The Carers Strategy 'refresh' (2010) rightly expects that young carers should be able to achieve their full potential and have the same opportunities as other young people with regard to education and training, future employment, relationships and family life. In achieving this goal, young carers should not of course be expected to carry out unreasonable levels of care or inappropriate caring tasks.

There has been widespread welcome for the Government's significant steps in strengthening the rights of *adult* carers within the Draft Care and Support Bill. We hope that *young* carers' rights and roles will be similarly strengthened and that there will be compatibility between the Draft Children and Families and the Care and Support Bills. In particular, we hope that we can use this significant opportunity to raise the concept of *whole family* preventative approaches in both Bills to ensure that young carers do not undertake inappropriate levels of care and that whole family assessments and care planning maximize quality of life and achieve outcomes to the benefit of all concerned. We also note that many young carers will over time become *young adult* carers and longer term planning for the whole family will be vital for their well-being during and beyond this transition period.

Question 10: The 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 cannot easily 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). The Standing Commission's recent fact finding visits have clearly demonstrated the value of a robust brokerage service (often provided through the voluntary sector) in enabling carers to make sensible choices about care and support options. Importantly, we note that the availability of brokerage services for those who want them encourages both positive and proactive attitudes towards personal budgets and direct payments and better use of mainstream community assets.
- c) **We welcome the specific inclusion of self funders** (the numbers of which are likely to increase substantially over the next decade). We would hope that information and advice will be seen as a service universally available to all potential users and carers (in effect to local communities) and quite separate to any local arrangements around eligibility for support. We note the potential cost to both the local authority and the NHS if self funders make poor choices about care services, with early admission to care homes or in some cases family breakdown.
- d) **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 acknowledge the concerns that have been expressed about the need to balance local authority responsibility for delivering a comprehensive service with ensuring the independence of that service from the local authority itself as commissioner and in some cases provider. We recognize that many of the best information and advice services currently available are

managed through the voluntary sector, eg through Carers Resource Centres, Centres for Independent Living, the Carers Trust and others. Many of these services are already commissioned by the local authority, in some cases in partnership with the NHS. The delegation of information and advice services to such bodies may well represent 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.

- e) **We also 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 actual services and ensuring safety. These are of course prime areas of concern for carers, but we would also like to see this section of the Bill strengthened in order 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 additional sub-section along the lines of:
- (x) How people can help to prevent the need for care and support from developing and thereby increase the scope for rehabilitation and maintenance of maximum independence of the person needing care and support 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 hope that information and advice will be provided as a universal service but could see charging for such services as a potential disincentive to both users and carers. We assume that Local Authorities would not normally seek to impose specific 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.

With regard to Question 5 (integration of care and support with housing), we note the importance of information and advice on housing options for older and disabled people. The provision of a stairlift and often minor adaptations to an existing home may eliminate the need for personal care and support. Similarly information on sheltered or

accessible housing options can transform lives. We hope that guidance will encourage local authorities to work with and support the growing number of voluntary sector housing advice services. We also note the potential of personal budgets to assist with costs of equipment (including telecare or telehealth) or small home adaptations. These practical resources may not only reduce the level of care on the family, but they will very importantly maintain maximum independence and confidence in the person needing care and support.

Creating accessible homes and funding home improvements: Remaining in your own home for as long as possible is a high priority for the majority of people needing care and support and their families. However, many older people will find this problematic without investment in adaptations (grab rails, downstairs showers, ramps, stairlifts etc.). If local authorities are expected to ‘*do more with less*’ and if (as is clearly the case) we are going to see more self funders, then local authorities could be usefully encouraged to consider how they might help those self funders release capital from their often fixed assets in order to fund adaptations and home improvements themselves. We emphasize this point because many families, albeit asset rich, are income poor. Currently financial services in the UK (unlike in our EU counterparts) discriminate heavily against older people. It is impossible for carers or users to get bank loans, even for modest amounts, if they are 75 or over (even if income and house values could easily support such a loan). We have in the past seen some local authorities introducing loan schemes for adaptations as a preventive strategy. Interest is charged at an appropriate rate and in some cases the loan is taken as a charge on the value of the house. The investment reduces the need for care and support in many cases and avoids premature admission to residential care. We would welcome encouragement for more ‘*self-help*’ initiatives of this kind.

With regard to this new duty, we also that guidance will encourage local authorities to see information and advice as important **preventive** services. Historically access to social care and support has often been crisis driven with opportunities for earlier low-level support missed. Demographic change means that not only will the number of carers increased. They are also likely to be caring for longer. Hence high quality information and advice will be vital to avoid expensive breakdowns in care and support.

Question 11: 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 in their areas 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.

Question 13: Developing an 'asset based' approach within the Care and Support Bill

We welcomed the intention to '*promote support within communities*' as set out in the White Paper and the linked proposal to consider '*asset-based approaches*' to encourage better use of community support and resources rather than more traditional models of care and support wherever possible. However, we do not think that the Bill at present goes far enough in supporting a shift from a traditional care management system to one which is '*asset based*' and focused more on individual choice, empowerment and control.

We recognize that at present we have a complex system, with responsibilities, eligibility and access to services resting variously on the state, the community and the individual. The personalization agenda offers the opportunity to look more widely at how we interpret care and support and how we can provide much earlier support to enable carers and users to:

- a) Find innovative ways of using local mainstream resources (for example volunteers, time-banking, community and leisure services);
- b) Have access to information and advice in order to make sensible choices;
- c) Develop the confidence and resilience to '*do things differently*' through seeing care and support as positive and proactive rather than services provided only on a deficit model. As one carers' group said on a recent Standing Commission Fact Finding Visit, '*the present system rewards you for failing. You have to prove you can't cope rather than starting from the perspective of how to ensure that you can cope and feel in charge of your life and that of the person you are looking after.*'
- d) The same carers' group suggested that '*we have to shift the system away from proving eligible need (and thereby often needing to exaggerate problems) towards more proactive planning. That planning should and could involve exploring how you can still continue to enjoy the things you used to, still go to work etc. but it is likely to involve much more flexibility and much more contact with your local community. The planning must be followed by a record of intentions and the start of a care pathway, setting out what you want to achieve and the steps for achieving it.*'

In effect, we need to look more broadly at how we interpret 'well-being' and what we mean by 'assessment'. We suggest that three tests for a broader asset-based approach towards assessment and care planning should include:

- **The ability to live daily life in safety and with dignity**
- **The ability to maintain relationships with family and friends (ie to enjoy family life)**
- **To engage with the community as an active citizen and to pursue and sustain employment if so desired.**

Whilst we recognize that there will always be a need for a statutory assessment system in some cases, we hope that guidance will encourage a broader asset-based approach for the wider range of carers and those they support. In this context we also hope that guidance will encourage links with public health (through the Health and Well-Being Boards and the JSNA) and with the wider range of health and educational facilities in the local community. We see proactive ‘*asset-based*’ strategies as key to providing much earlier and preventive intervention and support and crucial to improving take-up of (and confidence in) personal budgets.

Questions 14-18: Assessment and Eligibility for Social Care

We strongly support the proactive focus on *outcomes* within the proposed assessment arrangements (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:

- a) 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 and anticipate that this will 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. With the emphasis on personalization and on community participation within the Bill (and related ambitions for the future of social care), we see transport as a core service. Although we give transport and equipment as

examples of potential responses to assessed needs, we anticipate that regulations and guidance will clarify and further expand the interpretation of Clause 8, given the importance of encouraging a more diverse range of personalized solutions to care and support.

b) **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 (and proportionate) 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.’**

c) **Delegation of assessments:** If, as is proposed, 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 both the individual and family in question and the assessor should be suitably qualified and experienced. In our recent fact finding visits, we have noted a number of initiatives to provide early ‘triage’ assessments through a carers’ centre or similar voluntary organisation, with the ability of the ‘triage’ assessors to provide immediate low levels of support. These delegated first-tier assessments and their responses are funded via the local authority (sometimes in partnership with the NHS) and not only give a rapid response to expressed need but also appear to reduce demands for more formal procedures. However, the local authority retains overall responsibility and carers can request a second tier carers’ assessment if they so wish. We hope that the guidance relating to the Care and Support Bill will encourage similar partnerships (recognizing the resource implications for such delegated responsibility).

d) **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, in addition to ‘hands-on’ physical care. Such support may be vital in terms of maintaining independent living and minimizing dependence on paid services, eg help with financial issues, planning and shopping for food, transport or assistance with

mobility and in many cases the management of a direct payment or personal budget..

- e) **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 potential impact on wider family members. In particular, we note the implications of the improved life expectancy of people with learning disabilities and the emergence of a group of carers who will have had life-long caring roles which extend into their own old age and potential fragility. 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.

- f) 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. As noted above, we note that many carers now provide care and support over decades because of improvements in medical care.
- g) **Family-focused assessment:** 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. With regard to Clause 12(3), we also 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. We fully accept that at times the views of the user and the carer or carers may differ. However, we also

believe that good information, appropriate advice and advocacy if required, will resolve most difficulties and will also make best use of available resources.

- h) 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* system¹ 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 any major development in assessment for care and support.
- i) **Strengthening the whole family approach for young carers:** 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.

However, we also hope and commend that the principle of whole family assessments should be applied more widely and warmly welcome the growing support for the concept of whole family approaches and joined up assessments and care planning. In particular, we would welcome the inclusion of a *Whole Family Pathway* or whole family assessment process within guidance and regulations as appropriate. This is to some extent provided for already in Clause 12, but we feel this could be strengthened.

¹ An example of the Whanau Ora Pathway is given on whanauora@tpk.govt.nz. The products of the Ministry of Social Development Task Force on Whanau are available via whanauora@msd.govt.nz

Question 15: Identification of carers

- a) We recognize that the first opportunities to identify carers will often occur within the NHS and with GPs in particular. We have been greatly encouraged by the RCGP's proactive work in this area and by the increase in numbers of carers on GP registers, together with the development of Carers Champions in many practices. We have also seen some very positive partnerships between the local authority and primary care services in their area, with GPs able to refer carers to local voluntary organizations for early information, advice and in some cases a direct service. We hope that guidance and regulations will encourage such partnership arrangements and thereby ensure that carers are better informed and supported right from the start.
- b) In this context, we see the new duty on local authorities to provide/facilitate the provision of information and advice services as particularly important. At present many carers simply see no point in discussing their role with any professionals because they assume there is no support available. A good information and advice service should encourage and empower carers in acknowledging their role and in knowing how to access support (whether self funded or not). If that information and advice resource is well developed and publicized, carers are likely to come forward. In this context, we want to emphasise the importance of information and advice as *preventive* services, often enabling carers to identify low-level mainstream support and maintaining ordinary life for as long as possible.
- c) Health and Well-Being Boards (and of course the JSNA) already give new opportunities for joint working in order to identify areas of need in the local population – both the Care and Support Bill and the NHS legislation/Mandate constitution encourage greater integration and co-production and hopefully carers will be identified and recognized as proactive partners in the new outcome focus of both health and social care.
- d) A new *family* focus in assessment (and the Bill's introduction of parity of esteem between carers and those needing support) should enable local authorities themselves to probe rather more deeply than at present as to whether there is a family carer around. The Bill, by introducing the concept of a care and support plan for carers as well as those they support, should help earlier identification of, for example, a distance carer. Historically, when assessment has focused on the person needing the support, there has often not been any contact with (or information for) carers and no incentive to self identify.

- e) We hope that the introduction of care and support plans will always be accompanied by a discussion as to whether there is a family carer who will be affected by, or contribute to, the package of support proposed. We recognize that there is still a major communication task to be carried out in terms of raising the profile of the carers who offer informal care and support. Many carers, even those providing high level care, do not see themselves as ‘carers’. However, if assessment becomes more *family* orientated, we hope that the numbers of carers who self-identify will increase.

Question 16: Variable local charging regimes and national eligibility criteria

Currently there are unacceptably widespread variations in charging policies and some confusion as to whether services charged for are intended for the benefit of the cared for or the carer. We are particularly concerned to hear about users and carers who are refusing support because they feel that they cannot afford the charges imposed locally (with consequent risk to their health and that of their relative and the escalating risk of family breakdown or recourse to residential care). We recognize that charging must be a reality for many users and carers but feel that charging policies, like eligibility criteria, should be developed within a national framework that is transparent and fair. If there are local variations (for example due to the considerably higher costs of care in London and parts of the South East), then these charges should still reflect national guidelines and be seen as reasonable by those asked to pay.

As healthcare is free at the point of delivery, but social care may be subject to most-testing in many cases, we also hope that regulation and guidance can resolve some of the current challenges around criteria for continuing health-care and the regional variations in determining eligibility.

We hope that guidance and regulations will consider further how financial assessments are carried out, with reference to any charges imposed on services. We note that many families have multiple caring roles (which may involve distance caring with attendant costs of travel and possible loss of earnings).

Questions 14-18: Assessment and Eligibility for Social Care

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.

The risks and benefits of self assessment for care and support: We are aware that many disabled people already self-assess for their care and support and have no problems with either identifying their need for support or the options for providing such support within the financial guidelines set by the local authority. However, we are equally aware that many users and carers will wish to have (and benefit from) information and advice and, in many cases, the role of the social worker in considering options. All carers and users should be encouraged to be active participants in any assessment arrangement and we hope that the new duty on Local Authorities to provide information and advice services will ensure that assessments become more proactive, genuinely personalized and more creative in their outcomes.

The 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) **The basis for calculating charges (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 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 and that regulations will clarify how financial assessments are carried out (taking into account the often multiple caring roles of carers).

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.

Question 18: Setting and enforcing national minimum standards

We hope that standards and related guidance will be set to ensure that there are both high expectations of social care and clear messages to providers and commissioners about the quality of care and support services expected. However, we do not see *minimum* standards on their own as sufficient to guarantee quality and would prefer the model of the new social care quality standards as developed by NICE together with practical guidance to assist both local authorities and the NHS in their market shaping duties. Although this is a Bill relating to social care and support, we hope that guidance will encourage parallel initiatives in health services with regard to the new plurality of the market and the shift to personalized services.

In terms of setting and enforcing standards, we hope that guidance and regulation will encourage the development of good relationships between the national strategic partners in ensuring quality and safety of care and support for users and carers. NICE's role in developing and setting standards for social care will be ineffective without strong partnerships with CQC, the NHS Commissioning Board, Public Health England, the National Quality Board, Monitor, Healthwatch England and others (including the professional regulatory bodies).

Additionally, we wish to emphasise that compliance with *minimum* standards is an insufficient guarantee of quality and safety in the provision of care and support. We hope that there will be strong incentives to continuously drive up improvement in the

quality of care and support. This in turn will entail robust and open discussions between commissioners, providers, users and carers and the regulatory bodies, together with recognition that good regulatory frameworks and high standards must be co-produced.

We consider it vital that users and carers are seen as key players within standard setting and the regulatory framework. Their personal experiences and views are vital if we are to aim for continuous improvement rather than static compliance with minimum standards. As CQC (2012) comments in its strategic review, we need to:

'...use their [users and carers] views, experiences and concerns more systematically'

In inspecting and acting on both poor practice and in identifying and promoting what works well.

Skills for care: We also note that the skills and qualification of staff are very relevant to the delivery of quality services and hope that guidance will take forward the current work on training and professional development for a broad range of care staff (including personal assistants).

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' support ends and where support for the person needing care begins.
- 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.

Question 19 - 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 needing care 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 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 warmly 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. In many cases joint assessments and the resultant plans for support will be welcomed by both carers and users and ensure the best possible outcomes for both.

- 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 could be a new and potentially burdensome task in managing the audit trail for the budget and also in 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. The need for care and support is not necessarily static and many people with long term conditions will require escalating levels of support over time.
- 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, adult family placements to care homes). We also hope 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.

Question 20/21: 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 not only to the initial planning arrangements but also to subsequent 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 are not static. 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 learning or other disability. In these cases, the ability of the family carers themselves may also 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.

Protecting users and carers from ‘care by the minute’ and rigid care practices:

We share the Committee’s concerns at the rigid micro-delivery of care to some people needing support and their families. Good quality care depends on relationship development as well as on actual delivery of care and support services. We hope that care and support plans will not only specify what and how care will be provided but will also have a robust review process to ensure that both user and carer would positively apply the ‘*friends and family test*’ proposed for the NHS. In effect care plans should be seen as living documents, organic, capable of modification if appropriate and setting outcomes against which progress can be measured.

Question 20: Personal Budgets, Direct Payments and Choice and Control

We are very 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, as noted below:

- 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. In this context we also hope that guidance will encourage local authorities to ensure that there are practical sources of help and advice in both designing and

managing a personal budget or direct payment. We note the effectiveness of partnerships between local authorities and Centres for Independent Living and other voluntary sector organisations in this context. We are aware that many carers are currently worried by the potential responsibility of money management; are unsure what to purchase or how to manage a personal assistant if recruited and are anxious about using new and unfamiliar sources of help. However, we have no doubt that with encouragement and support many carers will welcome the greater flexibility of personalization and personal budgets and, in many cases, will use community rather than specialist services with confidence.

- 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. We note that in other European countries it is commonplace for the equivalent of personal budgets to be used either for 'whole family' purposes or to compensate another family member for loss of earnings. We are aware of some concerns about the apparent payment of family members, because of the potential for exploitation or misunderstanding on both sides, but feel that this should be further explored in guidance.

As a general point, we hope that guidance will acknowledge the challenges of providing care and support in an increasingly diverse society. Different BME communities may have culturally different and distinct views on family roles as carers and also in their preferences for particular types of support. In many cases engagement with those communities will best come through community groups and the voluntary sector. We are also aware of the risk of assumptions being made about unwillingness to use care and support services without proper consultation with the communities in question and clarification as to the type of support that would be acceptable.

We would welcome an emphasis on equality issues and the need for sensitivity with regard to designing and commissioning personalized services in different communities within the forthcoming guidance and regulations.

Question 22: Safeguarding adults at risk of abuse of neglect (Clauses 34 and 35)

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. We have a number of points with regard to safeguarding as set out below:

- a) **Clause 35:** We warmly welcome 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.
- b) **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 are concerned 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.
- c) **Relationship between the Safeguarding Adults and Health and Well-Being Boards:** In the same Clause, we would also 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.
- d) **The introduction of a new offence of corporate neglect:** In principle we support the proposals to create a new offence of corporate neglect, recognizing the failures of the company responsible for Winterbourne View and the growth of a wide range of commercial care service providers, often managing services at a distance and not necessarily as engaged as they should be in the quality of care

offered. We would welcome further consideration of this new offence and the advantages (or otherwise) of collective as opposed to individual responsibility.

We hope that guidance and regulation will address the interface between the role of the Safeguarding Adults Board, the local Healthwatch and the relevant regulatory bodies. As we have noted with regard to Question 18 (setting and enforcing national minimum standards), we hope that guidance and regulation will encourage the development of good relationships between the national strategic partners in ensuring quality and safety of care for users and carers.

In effect, the ability of Safeguarding Adults Boards to protect vulnerable people and to ensure compliance with new standards for social care (such as those developed by NICE) will be largely ineffective without strong partnerships with CQC, the NHS Commissioning Board, the National Quality Board, Public Health England, Monitor and Healthwatch England.

Safeguarding Adults Boards should be seen as key components in the early identification of potentially poor or abusive practice. The CQC strategy review (2012) makes reference to the importance of learning and improving as core components in monitoring, regulation and safeguarding and notes the accompanying need to '*foster an open culture which encourages dialogue and constructive conversation so as to advance understanding.*' We are also aware that many carers, users and patients wish to raise issues *before* they have become formal complaints and to engage in the '*dialogue and constructive conversation*' referred to above at an earlier stage to avoid an escalation of difficulties and possible system failure. In this context, carers, users, patients, providers, commissioners and communities need to understand '*what good looks like*' and inspections should explore how constructive dialogue can take place in advance of formal complaints.

We note that the welcome emphasis on personalised services and integration in families and communities raises additional issues for Safeguarding Boards. We hope that the Safeguarding Boards will not only be *reactive* to local concerns, but will also be *proactive* in terms of promoting proportionate risk management. Good risk management might include local policies and practice around the recruitment and training of volunteers; improving community safety and better training for police and other community workers. This approach can only be successful if there is genuine engagement with local carers, users and the wider community and we hope that guidance will explore the challenges and opportunities inherent in such an approach.

In this context we also think it is important that the Safeguarding Boards and Healthwatch at local level (and CQC and other regulators at national level) should

ensure that users and carers have good quality and accessible information on what they should expect from a service and how they should raise any concerns.

Question 26: Promoting integration of care and support with health services etc

We welcome Clause 6, which promotes integration of care and support with the NHS. We note that the inter-dependence of health and social care is vital 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 NHS Mandate.

- a) **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.
- b) **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.
- c) **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.
- d) **With regard to hospital discharge, we would welcome greater clarity within regulations and guidance as to the arrangements made prior to discharge for any support and any arrangements for reablement.** We note that hospital discharge is only one point (albeit a very important one) on a patient's care pathway and that the care and support offered before and after discharge to the patient *and his or her carer* will be vital to good outcomes.

Whilst we welcome the introduction of the '*Friends and Family Test*' for patients, with regard to their experiences on the ward during their recent hospital admission, we are concerned that the *families'* experience of such care is not included within the test. As the Winterbourne View Serious Case Review noted,

parents' views were positively discouraged and disregarded, whereas attention to their concerns could and should have helped prevent the poor care and incidents of abuse.

- e) **We would welcome the inclusion of *reablement* within regulation and guidance with a view to ensuring that it is a genuinely integrated service that maximizes independence and accesses any necessary care and support not only in the immediate post-discharge period but if necessary on a longer term basis in the community.** Carers have a vital role in any reablement scheme but frequently tell us that they do not feel fully involved and that health professionals do not necessarily understand the impact of caring on their own health and well-being. During our recent fact finding visits, we have seen positive examples of local carers' centres working with carers *on the ward* after a relative's admission following a stroke or other incident. We have seen designated nurses with specific roles in ensuring that carers are partners not only in the acute recovery phase but are well prepared (and supported) in and after the discharge process. We have also seen evidence of the growing significance of proactive reablement schemes in maximizing recovery and a return to family and community. In this context we note that many carers take up their caring roles after a traumatic admission to hospital and the discharge of a relative who is now disabled or otherwise significantly affected by the cause of the admission.
- f) We hope that local authorities will be encouraged to ensure that information and advice services take account of the importance of information and advice around hospital discharge and that guidance will encourage the Clinical Commissioning Groups to work with their local authority counterparts in developing integrated information services where appropriate.

As noted above, we have warmly welcomed the proposed introduction of the '*friends and family test*' for NHS services. However, we would firstly like to see that test broadened to include the views of *carers* (particularly in cases where the patients or users have poor communication abilities) and to see greater weight places upon carers' views of both health and social care and support. We also hope that the regulatory bodies (as well as individual services) will pay greater attention than in the past to the actual experience of care and support from the perspective of both user and carer. We have commented in greater detail on the relationship between carers' views and monitoring and regulation in our comments on safeguarding above. We are aware that much more effort is being made to capture the personal experience of those using services and of the relevant families and carers. However, we would still welcome a more proactive use of '*experts by experience*' in reporting to local authorities, the NHS

and of course to providers on what is working well, what are the barriers and thereby improving local commissioning arrangements and prevention strategies.

In seeking the views of patients and carers, it is also vital that both understand their own rights and entitlements within the NHS. We have welcomed the NHS Constitution and the associated NHS Mandate (although we regret that neither is currently well known in local communities). Although it is outside the scope of this Bill, we would have welcomed a similar Constitution for Social Care and Support (or indeed a joint Constitution between the two). The NHS Constitution rightly not only specifies entitlements but also sets out the reciprocal rights *and responsibilities* of local citizens. It furthermore is intended to be a living document, reviewed and renewed every ten years, with the involvement of the public, patients and staff. It is based on sound principles and values and we hope that the Care and Support Bill will similarly redefine the collective rights and responsibilities of those using, providing and commissioning care and support. We note that carers are probably the greatest resource available to both the NHS and social care and hope that the new emphasis on integration and co-production will ensure that they can achieve the outcomes set out in the Carers Strategy Refresh (2010).

In conclusion

The Standing Commission on Carers recognizes the unique opportunity offered by the draft Care and Support Bill to rethink and hopes that it can work with the Government and the Department of Health in ensuring that the 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. In particular we warmly welcome the opportunity to achieve parity of esteem both for carers and for those they support and to see both as valued 'co-producers' in the transformation of the system for care and support.

Dame Philippa Russell,

Chair,

Standing Commission on Carers,

E-mail: prussell@ncb.org.uk

scoc@dh.gsi.gov.uk

