

# CARE & SUPPORT ALLIANCE

## Draft regulations and guidance on eligibility Care & Support Alliance response

Contact: Caroline Hawkings – Care & Support Alliance Lead on Eligibility  
[caroline.hawkings@scope.org.uk](mailto:caroline.hawkings@scope.org.uk)

### **The Care & Support Alliance (CSA)**

The Care & Support Alliance was set up in July 2009. It is a consortium of over 70 organisations that represent and support older and disabled people, including disabled children, those with long-term conditions and their families, and campaigns to keep adult care funding and reform on the political agenda.

### **Introduction**

The CSA is pleased to have been working with the Department of Health on the development of the eligibility regulations and guidance (and other aspects of the Care Act). We welcome many of the changes that have been made, although this response mainly focuses on outstanding concerns and suggests ways of addressing them.

### **List of Recommendations on the Regulations**

#### **Amendment to Clause 2 (1) for adults**

2.—(1) An adult's needs meet the eligibility criteria if the adult's needs *relate to or arise from* a physical or mental impairment or illness and as a result of the adult's needs –

- (a) there is, or is likely to be, a significant impact on the adult's well-being; or
- (b) the inability of the adult to achieve an outcome specified in paragraph (2) has, or is likely to have, a significant impact on the adult's wellbeing.

*This has the effect that significant impact on wellbeing has to be considered in relation to the wellbeing principle in its entirety and not just in relation to the specified outcomes. It also better reflects the requirements of the Care Act which are;*

9(4) A needs assessment must include an assessment of—

- (a) the impact of the adult's needs for care and support on the matters specified in section 1(2)<sup>1</sup>
- (b) the outcomes that the adult wishes to achieve in day-to-day life

<sup>1</sup> Section 1(2) being the areas covered by the wellbeing principle

### **Amendment to Clause 3 for carers**

**3.—(1)** A carer's needs meet the eligibility criteria if—

- (a) the needs arise as a consequence of providing care for an adult; and
- (b) paragraph (2) or (3) applies.

(2) This paragraph applies if the effect of the carer's needs is that the carer is unable to provide some of the necessary care to the adult needing care.

(3) This paragraph applies if—

- (i) *there is, or is likely to be, a significant impact on the carer's 's well-being; or*
- (ii) the effect of the carer's needs is that any of the circumstances specified in paragraph (4) apply to the carer; and
- (iii) as a consequence of that fact there is, or is likely to be, a significant impact on the carer's well-being.

#### **In addition,**

- The eligibility regulations should explicitly refer to all aspects of the well-being principle in Section 1 in relation to adults and carers
- Guidance should include information on factors to be considered when making decisions about significant impact in relation to adults and carers

### **Omissions from the current draft criteria**

#### **Communication**

- 'Communicating and expressing oneself' should be explicitly added as a specified outcome for the adult, to those listed under 2 (2) and information added to the guidance.

#### **Staying safe from abuse or neglect**

- The eligibility criteria should be amended by adding to Clause 2 and Clause 3 a new sub-clause:  
'An adult's/carer's needs also meet the eligibility criteria where abuse has occurred is or will occur'.

*This is to avoid creating a threshold for support to stay safe and having to meet the requirement for staying safe to have a significant impact on a person's well-being.*

- The safeguarding guidance should be strengthened to ensure that individuals at risk of, or who have experienced, abuse or neglect can get the support they need to stay safe

## **Recommendations on the draft regulations clause by clause**

### **Clause 2 (2) Specified outcomes**

#### **Clause 2 (2) (3) 3 (4) (b) (i) basic care activities**

- If the intention is that 'some or all' means 'two or more', its meaning should be made clear in guidance.
- Guidance for adults should clarify the meaning of 'some or all' basic care activities in relation to other comparable care activities and cumulative impact (paragraph 6.86).
- Guidance for carers should clarify the meaning of 'some or all' basic care activities in relation to other comparable care activities and cumulative impact.

#### **2 (2) (b) and 3 (4) (b) (iv) maintaining family or other significant relationships**

- This outcome should be amended to read '*developing and maintaining family or other relationships.*' This should also be made clear in the guidance.

#### **2 (2) (d) and 3 (4) (b) (v) accessing necessary facilities or services in the local community including medical services, public transport, educational facilities and recreational facilities or services**

##### **Recreational activities**

- For adults 2 (2) (d) "recreational facilities or services," should be amended to "recreational facilities or activities," to ensure consistency and guidance should make clear that this includes support for activities like going out for a walk.

##### **Access to medical services - Transport**

- 'Access to medical services' should be retained but with several crucial changes to guidance:
- Guidance should clearly state this clause in the Care Act is not changing any existing NHS responsibilities – this includes for example:
  - Regulations s75 on hospital transfer
  - The provision of an interpreter at a hospital appointment covered by a reasonable adjustment under the Equalities Act
  - Co-ordinating appointments if a person has several eg this is the role of the Care Co-ordinator if people with mental health problems are under the Care Programme Approach
- Guidance should clearly explain with examples, what access to medical services means from a social care perspective: ie that it is about support to access the medical services, not eligibility for the medical service itself.
- Guidance should make clear that support to access medical services and facilities must be exempt from charging.

##### **Carers**

- Clause 3 (4) (b) (v) - any rewording should retain the principle that carers should be eligible for support where, as a result of the care they provide, they are not able to attend medical appointments
- Relevant sections of the Care Act guidance should clarify the meaning of 'making use of' and clearly (re)state what existing NHS duties are, including cross referencing other the relevant legislation and guidance

### **Access to medical services - supervision and prompting to take medication**

- Guidance should cross-refer to paragraph 6.67 on assessment that social care should only be provided to meet “incidental or ancillary needs,” not primary health needs.
- Guidance should provide clarity on the circumstances in which supervision and/or prompting a person to take medication can be a legitimate social care responsibility and when it is not. If in some circumstances social services do deliver this, it should be expressly excluded under new charging guidance.
- Similarly guidance must be clear that this clause is about accessing medical services, not administering medication.

### **Clause 2 (3) basic care activities**

- To make clear that the list of basic care activities in the adult criteria is not exhaustive and to strengthen the guidance that local authorities can consider other comparable activities, 2 (3) should be amended to read ‘basic care activities’ means essential care tasks that a person carries out as part of normal daily life including, *but not limited to* -
- Shopping should be a specified task coming under basic care activities rather than assuming that this is covered under access to facilities.

### **The cleaning and maintenance of one’s home**

- Cleaning and maintenance of one’s home should be split into at least two categories. We suggest that these should cover 1) cleaning and maintenance – eg. to include cleaning, maintenance, repairs and gardening and 2) sustaining a tenancy – eg to include managing household finances and bills and support to prevent hoarding which can lead to eviction. This applies to the adult’s and carer’s criteria.

### **Outcomes-focused basic care activities**

- The CSA finds the definitions of ‘basic care activities’ expressed as outcomes as proposed in the consultation document unhelpful and difficult to implement in practice. We conclude that ‘basic care activities’ should not be defined as outcomes.

### **Clause 2 (4) Clarifying the meaning of assistance**

- Regarding 2 (4) (a) and subsequent clauses, “unable to achieve (it) without assistance”, it should be clearly spelt out guidance that this includes “needs prompting or supervision”.

### **Section 2 (4) (b) – adults and section 3 (6) (b) (i) carers refer to ‘significant pain, distress or anxiety’**

- Section 2 (4) (b) for adults and section 3 (6) (b) (i) for carers should be amended to refer to ‘significant pain, *fatigue*, distress or anxiety’

### **Specific recommendations relating to carers**

#### **3 (4) (b) (vii) Access to leisure**

- The wording should be changed to “leisure activities” as in the current law.

#### **Young carers**

- If all three conditions need to be met for an adult to be eligible for care and support, all three conditions must take into account the impact on the child (their parenting responsibilities and functioning of the family). This raises particular concerns with condition 2.1.(c) which only relates to the impact on the adults wellbeing.
- We welcome the intention that the outcomes consider the caring responsibilities of adult and understand this was intended to consider an adult’s parenting responsibilities. However, the term is ambiguous and can be confused only to relating the children with care and support needs. 2. 2(e) must clearly reference parenting responsibilities in order to avoid any confusion.
- We welcome the intention to consider the impact on any children in the family which is indicated in 2.4(c) and expanded on in guidance. It is essential to make it clear that in reference to children endangered reflects the guidance elsewhere that a young carer/ child becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.

## **Full submission**

***Q14. Do the draft eligibility regulations, together with powers to meet other needs at local discretion, describe the national eligibility threshold at a level that will allow local authorities to maintain their existing level of access to care and support in April 2015? If you believe they don't please explain your reasons for this.***

The CSA understands that the Government's intention is for regulations to set the national minimum eligibility threshold at the equivalent of substantial FACS, the level currently adopted by the majority of councils. In our view, this threshold is too high and will exclude carers, older and disabled people from essential support. We believe that the threshold should be set at the equivalent of 'moderate' FACS, with sufficient funding for local authorities to meet their duties under the regulations.

### **Clause 2 of the regulations for adults**

In relation to adults, we believe that the proposed regulations represent a tightening of the current 'substantial' level of care, due to the conditions set out in Clause 2 of the regulations. In addition to having a physical or mental impairment or illness, and being unable to achieve a specified outcome, this then has to have an impact on well-being which is significant. Arguably, this amounts to four conditions, which we fear will continue to exclude people who require care and support, such as people with sight or hearing impairments, people on the autistic spectrum and those with mental health problems or mild to moderate learning disabilities.

Furthermore, as currently drafted well-being is used in a very limited sense. Significant impact on well-being is only considered in relation to the specified outcomes listed, not all the outcomes of in the well-being principle in Section 1 of the Act.<sup>2</sup> In effect, the eligibility criteria are acting as a filter for the wider well-being principle. It would be helpful for guidance (or good practice examples) to include information on factors to be considered when making decisions about significant impact. This could be done with reference to:

- Measures of wellbeing in Public Health already being used to measure well-being at a population level.<sup>3</sup>
- Reminders that the individual is the most appropriate to decide impact (or a Best Interests person if the adult without capacity) and that it is not the cause of the impact, but the nature of it which is important.

### **2 (1) (a) the adult's needs are caused by a physical or mental impairment or illness**

We believe that in some instances it may be difficult to demonstrate that an adult's needs are caused by a physical or mental impairment or illness. We are concerned about people who clearly have care and support needs, but whose impairment or illness is as yet undiagnosed or in dispute. This applies particularly to people on the autistic spectrum and those with a range of personality disorders.

We suggest adopting the wording 'arising from or related to' from Section 75 of the Care Act, instead of 'caused by'.<sup>4</sup> This would also be consistent with the carer's eligibility criteria, where Section 3 (1) (a) states 'the needs arise as a consequence of providing care for an adult.'

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<sup>2</sup> Section 1 (2) of the Care Act

<sup>3</sup> See for example: Measurement of mental health, outcomes and key sources of data, Faculty for Public Health: [http://www.fph.org.uk/measurement\\_of\\_mental\\_health%2c\\_outcomes\\_and\\_key\\_sources\\_of\\_data](http://www.fph.org.uk/measurement_of_mental_health%2c_outcomes_and_key_sources_of_data)

<sup>4</sup> s75 After-care under the Mental Health Act 1983 (5) (6) (a) 'meeting a need arising from or related to the person's mental disorder.'

Taking into account all the points made above, we suggest that regulation 2 should be amended as follows:

## **Recommendations**

### **Amendment to Clause 2 (1) for adults**

**2.—(1)** An adult's needs meet the eligibility criteria if the adult's needs *relate to or arise from* a physical or mental impairment or illness and as a result of the adult's needs –

- (c) there is, or is likely to be, a significant impact on the adult's well-being; or
- (b) the inability of the adult to achieve an outcome specified in paragraph (2) has, or is likely to have, a significant impact on the adult's wellbeing.

*This has the effect that significant impact on wellbeing has to be considered in relation to the wellbeing principle in its entirety and not just in relation to the specified outcomes. It also better reflects the requirements of the Care Act which are;*

**9(4)** A needs assessment must include an assessment of—

- (a) the impact of the adult's needs for care and support on the matters specified in section 1(2)<sup>5</sup>
- (d) the outcomes that the adult wishes to achieve in day-to-day life

### **Amendment to Clause 3 for carers**

**3.—(1)** A carer's needs meet the eligibility criteria if—

- (a) the needs arise as a consequence of providing care for an adult; and
- (b) paragraph (2) or (3) applies.

(2) This paragraph applies if the effect of the carer's needs is that the carer is unable to provide some of the necessary care to the adult needing care.

(3) This paragraph applies if—

- (i) *there is, or is likely to be, a significant impact on the carer's 's well-being; or*
- (ii) the effect of the carer's needs is that any of the circumstances specified in paragraph (4) apply to the carer; and
- (iii) as a consequence of that fact there is, or is likely to be, a significant impact on the carer's well-being.

#### **In addition,**

- The eligibility regulations should explicitly refer to all aspects of the well-being principle in Section 1 in relation to adults and carers
- Guidance should include information on factors to be considered when making decisions about significant impact in relation to adults and carers

<sup>5</sup> Section 1(2) being the areas covered by the wellbeing principle

## **Omissions from the current criteria**

The CSA believes that there are some serious gaps in the draft regulations and guidance, which must be addressed.

### **Communication**

As the regulations are currently drafted, a person's communication needs may only be considered eligible if they relate to one of the other specified outcomes – for example if a person is not able to access necessary facilities or services in the community because they are not able to communicate. However, the CSA believes that the ability to communicate and make oneself understood is a fundamental human right which has a huge impact on well-being and quality of life and must be included as a specified outcome in its own right.

CSA members are aware of people in different circumstances who need support but may not be eligible for it.

#### ***Example***

*People with profound and multiple learning disabilities (PMLD) whose families often have to top up pay for care workers to ensure that they get staff who have the skills to meet the individual's complex communication needs.*

*As most people with PMLD do not use any formal communication like words or signs, they need to be supported by suitably trained care workers to enable them to communicate. It is crucial there is a focus on their communication needs in an assessment, and a requirement to meet these specific needs, otherwise they are at risk of having staff who do not understand their way of communicating.*

*As Professor Juliet Goldbart has said, "Communication is a crucial human right because of its role in: our basic need for interaction with other people; supporting individuals' input into decisions that affect their lives; promoting greater independence in everyday life; allowing people to express their feelings and supporting people's participation in their community."<sup>6</sup>*

#### **Recommendation**

- 'Communicating and expressing oneself' should be explicitly added as a specified outcome for the adult, to those listed under 2 (2) and information added to the guidance.

## **Keeping safe from abuse and neglect**

We have summarised the key points here and refer to the separate CSA submission on safeguarding for further detail.

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<sup>6</sup> 'Communication and people with the most complex needs: what works and why this is essential' Goldbart and Caton (2010)

Under the FACS criteria 'abuse or neglect has occurred or will occur' is considered a substantial risk, and therefore anyone with any level of risk of abuse or neglect will be eligible for any support that would reduce or eliminate that risk (unless their authority sets their eligibility threshold higher than substantial). Under the current draft eligibility for the Care Act, risk of abuse or neglect does not appear in draft regulations as the intention is that safeguarding should not be subject to eligibility.

Whilst we can see some merit in this approach, the CSA is concerned about some vulnerable individuals who are at risk of abuse, who need support to prevent an incident from occurring and or who have experienced abuse or neglect who need support to stay safe. In both these situations, action to stay safe may require ongoing provision of support, rather than a one off intervention. We fear that such people who are currently eligible under FACS are likely to fall through the gaps of the safeguarding guidance and the eligibility criteria.

We do not believe that provisions in the Care Act under Section 2 (prevention) and Section 4 (Information and advice) will be sufficient to address these gaps. These services are universal and so are not tailored to an individual's specific needs and the person has no right to the ongoing support they may require.

### **Recommendations**

- The eligibility criteria should be amended by adding to Clause 2 and Clause 3 a new sub-clause:  
'An adult's/carer's needs also meet the eligibility criteria where abuse has occurred is or will occur'.

*This is to avoid creating a threshold for support to stay safe and having to meet the requirement for staying safe to have a significant impact on a person's well-being.*

- The safeguarding guidance should be strengthened to ensure that individuals at risk of, or who have experienced, abuse or neglect can get the support they need to stay safe

*This submission now considers the rest of the regulations in the order presented, dealing first with adults and then carers.*

### **Clause 2 (2) Specified outcomes**

#### **Clause 2 (2) (3) 3 (4) (b) (i) basic care activities**

##### **'Some or all'**

The meaning of this phrase is currently unclear and we are concerned that leaving it solely to local authority interpretation could result in variations in eligibility and subsequent care packages. This undermines the aim of a national threshold to improve equity and consistency across the country.

The change from 'one or more' in the draft regulations published in June and the 'some or all' in the current draft represents a considerable tightening of the eligibility criteria.

We believe that there are situations where person has a major need under basic care activities, but it may only be counted as one, as these examples illustrate:

### Examples

*Mr D has throat cancer and as a consequence, cannot eat or drink. However, he is able to carry out all the other basic care activities and other specified outcomes. In this instance, he should be eligible for care and support.*

*Mrs E, a lady with heart failure suffers from breathlessness on minimal exertion. She knows that she cannot do everything she needs to do to maintain a good quality of life, so she opts to do the things she considers to be of immediate importance. She paces herself, resting in between, and is able to maintain her personal hygiene, get to the toilet and ensure she eats and drinks. But because she can't do everything, she prioritises. To conserve energy, she doesn't wash her dishes, take her bins out or carry out any cleaning. She also keeps her food, including that which should be refrigerated, close to her for easy access. Soon, she becomes unwell and a family member takes her to A and E. Although she is currently found to be eligible for care under FACS, she would be ineligible under the criteria as drafted as she is unable to carry out only a single basic care activity.*

The phrase 'some or all' also needs clarification in relation to:

'comparable care activities': the statement in guidance that the activities contained in 2 (2) (3) are not an exhaustive list and that 'local authorities can consider other comparable care activities.' This is positive, but if a person is unable to carry out two activities which are not on the specified list of basic care activities, would they still be eligible?

The phrase 'some or all' is also important in relation to determining a carer's eligibility. Part of the consideration under 4 (b) is whether the carer is unable to carry out 'some or all' basic household activities in the carer's home (whether or not this is also the home of the adult needing care). The points raised in relation to adults also apply to carers

Cumulative effect: we are pleased that the guidance states that 'the cumulative effect of the impact on a number of the areas of wellbeing mean that they have a significant impact on the adult's overall wellbeing' (p87). This suggests that a person could require help with several basic care activities which individually do not have a significant impact on well-being, but do have a significant impact when considered together. If this so, it should be more clearly stated in guidance. The guidance needs to reflect this for carers too which does not currently refer to the cumulative effect of the impact of several areas on wellbeing.

### Recommendations

- If the intention is that 'some or all' means 'two or more', its meaning should be made clear in guidance.
- Guidance for adults should clarify the meaning of 'some or all' basic care activities in relation to other comparable care activities and cumulative impact (paragraph 6.86).
- Guidance for carers should clarify the meaning of 'some or all' basic care activities in relation to other comparable care activities and cumulative impact.

### **2 (2) (b) and 3 (4) (b) (iv) maintaining family or other significant relationships**

In our experience, many people using social care have difficulty in forming appropriate relationships including isolated older people or people on the autistic spectrum. Carers also find it hard to develop and maintain relationships because of the difficulty of getting out of the house and isolation is a problem for many carers.

We are also concerned about the value judgements which will have to be made by an assessor, about a person they may not know well, about whether a relationship is 'significant' or not. We suggest that if a relationship has a significant impact on a person's well-being under 2 (1) (c), it will by definition be 'significant', so this word is unnecessary.

#### **Recommendation**

- This outcome should be amended to read '*developing and maintaining family or other relationships.*' This should also be made clear in the guidance.

## **2 (2) (d) and 3 (4) (b) (v) accessing necessary facilities or services in the local community including medical services, public transport, educational facilities and recreational facilities or services**

### **Recreational activities**

For adults, the draft wording of 2 (2) (d) is "recreational facilities or services." Some disabled people have raised concerns as to whether support to go out for walk would be covered in this criterion.

#### **Recommendation**

- For adults 2 (2) (d) "recreational facilities or services," should be amended to "recreational facilities or activities," to ensure consistency and guidance should make clear that this includes support for activities like going out for a walk.

### **Access to medical services**

There are differing views on the inclusion of 'medical services' within this clause. There is concern that it may lead to an expansion of social care being inappropriately responsible for what should be NHS duties. This must be avoided. The CSA outlines our views in relation to two areas: transport and medication.

### **Transport**

Several CSA members have highlighted serious concerns about the difficulties people experience in getting to or from medical appointments and services, for example, a person who needs to see their GP cannot get there and the GP will not conduct a home visit, with the result that their health deteriorates. The inclusion of access to medical services will help to address these and other scenarios.

However the CSA is equally clear that the inclusion of access to medical services should in no circumstance lead to local authorities taking on duties which are an NHS responsibility. In the case of carers, this clause helpfully sets out an important principle that carers or those they care for should be provided with services which enable carers to attend medical appointments and have medical treatment etc. The exact wording needs careful attention to avoid creating further difficulties regarding the line between health and social care, but any changes should not lose this principle. The guidance should make clear that this is about ensuring replacement care is provided to allow carers to access medical appointments etc.

It is helpful for the guidance to clarify the meaning of 'making use of' and relevant sections of the guidance should clearly state what existing NHS duties are - for example in the chapter

on assessment that local authorities still have a responsibility to assess carers when the person they care for is under NHS Continuing Care. This will help to avoid an inappropriate shift of boundaries between social care and NHS responsibilities.

### **Recommendations**

- 'Access to medical services' should be retained but with several crucial changes to guidance:
- Guidance should clearly state this clause in the Care Act is not changing any existing NHS responsibilities – this includes for example:
  - Regulations s75 on hospital transfer
  - The provision of an interpreter at a hospital appointment covered by a reasonable adjustment under the Equalities Act
  - Co-ordinating appointments if a person has several eg this is the role of the Care Co-ordinator if people with mental health problems are under the Care Programme Approach
- Guidance should clearly explain with examples, what access to medical services means from a social care perspective: ie that it is about support to access the medical services, not eligibility for the medical service itself.
- Guidance should make clear that support to access medical services and facilities must be exempt from charging.

### **Carers**

- Clause 3 (4) (b) (v) - any rewording should retain the principle that carers should be eligible for support where, as a result of the care they provide, they are not able to attend medical appointments.
- Relevant sections of the Care Act guidance should clarify the meaning of 'making use of' and clearly (re)state what existing NHS duties are, including cross referencing other the relevant legislation and guidance

### **Supervision and prompting to take medication**

Although there are instances where the role of social services in regard to supervision and prompting to take medication may be appropriate, the CSA is also concerned that access to medical services could broaden social services responsibilities in this respect.

This is an inappropriate function of social services and could also lead to care users and carers being charged for what should be a free service under the NHS. We are extremely worried that the lines are becoming increasingly blurred as care users who use sophisticated equipment at home, which is usually found in hospitals, are liable to being charged because they are living in a domiciliary environment. Therefore it is essential that the guidance is as robust and as clear as possible and cross refers to the appropriate NHS legislation and guidance.

### **Recommendations**

- Guidance should cross-refer to paragraph 6.67 on assessment that social care should only be provided to meet "incidental or ancillary needs," not primary health needs.
- Guidance should provide clarity on the circumstances in which supervision and/or prompting a person to take medication can be a legitimate social care

responsibility and when it is not. If in some circumstances social services do deliver this, it should be expressly excluded under new charging guidance.

- Similarly guidance must be clear that this clause is about accessing medical services, not administering medication.

### **Clause 2 (3) basic care activities**

It is unclear where some tasks for which adults are currently receiving support will sit under the new criteria. Below, we outline some activities which a number of CSA organisations and older and disabled people themselves are uncertain about. This needs to be clarified mainly in guidance

- Assistance with reading food labels (possibly covered under preparing meals (3 (f)))
- Assistance with reading medication labelling (including converting medication labels in to Braille) and checking when prescriptions need renewing, is unclear.

### **Shopping**

- We believe that, as drafted, shopping does not clearly come under basic care activities or accessing necessary services and facilities. If it is implied in either of these categories, guidance should make it explicit.
- However, we recommend, both from a carer's and adult's perspective, that shopping should be an explicit basic care activity, because being able to get the food you need is essential and is different from being able to eat food. Shopping also includes purchasing a wide range of items.

### **Recommendations**

- To make clear that the list of basic care activities in the adult criteria is not exhaustive and to strengthen the guidance that local authorities can consider other comparable activities, 2 (3) should be amended to read 'basic care activities' means essential care tasks that a person carries out as part of normal daily life including, *but not limited to* -
- Shopping should be a specified task coming under basic care activities rather than assuming that this is covered under access to facilities.

### **The cleaning and maintenance of one's home**

The CSA warmly welcomes the inclusion of the cleaning and maintenance of one's home in the criteria and we believe it must be retained as this type of support is crucial to many of the client groups we are working with.

Furthermore, our strong recommendation is that this category should be expanded in both the adult's and the carer's criteria. The wording of the other basic care activities is fairly specific to a particular task. In contrast, (g) represents a broad range of possible tasks, but which as drafted, will only be counted as one 'basic care activity' for the purposes of determining eligibility. The current drafting means that people who are able to eat and drink and prepare meals etc, and have significant support needs, but only in relation to cleaning and maintenance of their home, will be excluded from receiving help. This will particularly disadvantage people with sight loss, or those with mental health problems, those with mild to moderate learning disabilities or some people with brain injuries for example. The regulations should be amended to address this unintended consequence.

### **Examples**

#### **Mrs C**

*Mrs C is 60 and is registered blind with a partial hearing loss, type 2 diabetes and a dust allergy. She lives with her husband who has mobility difficulties and is easily fatigued. They both work. Mrs C has been assessed as needing 5 hours care per week. Mrs C's support to maintain a dust free home and to ensure that is tidy to reduce the risk of falls, would come under 'cleaning and maintenance'. However it is less clear that her support for assistance with laundry tasks (hanging out washing and ironing) and changing bed linen and in dealing with correspondence would be covered by the draft criteria and because all of her needs come under the one category of cleaning and maintenance, she may not be eligible.*

#### **Mr R**

*Mr R has a learning disability and also has recently been diagnosed with heart failure. Local authority support workers prompt Mr R to complete household duties such as cleaning, laundry and maintenance of the property. Before support was put in place, he received help from a friend, but this became a strain on his friend's health and wellbeing and the relationship became borderline abusive.*

*Under the draft eligibility criteria, Mr R's needs may not be found eligible since he is able to carry out all other basic care activities. However, without support, his home is likely to become extremely unclean and potentially unsafe and Mr R is also at higher risk of having a heart attack.*

*Case study provided by Home Group, a member of the National Housing Federation*

### **Recommendation**

- Cleaning and maintenance of one's home should be split into at least two categories. We suggest that these should cover 1) cleaning and maintenance – eg. to include cleaning, maintenance, repairs and gardening and 2) sustaining a tenancy – eg to include managing household finances and bills and support to prevent hoarding which can lead to eviction. This applies to the adult's and carer's criteria.

### **Q15. Do you think that the eligibility regulations give the right balance of being outcome- focused and set a threshold that can be easily understood, or would defining "basic care activities" as "outcomes" make this clearer?**

The CSA strongly agrees with the ethos and aims of a care and support system which focuses on outcomes. However, we feel that to further define 'basic care activities' as outcomes would be inappropriate and unhelpful.

This is because at the stage of determining eligibility, the criteria, should be as fair, clear and transparent as possible and this is easier to achieve through a needs based approach. The definitions suggested in the consultation document are imprecise and dangerously open to different interpretations by assessors. This would undermine the aim of achieving more consistency, fairness and portability across the country.

However, the CSA is equally clear that the care and support pathway should be outcomes-focused. It is important that assessment and care planning are framed by conversations

about goals, outcomes and aspirations; conversations that are holistic and recognise and respect the whole-person.

#### **Recommendations**

- The CSA finds the definitions of ‘basic care activities’ expressed as outcomes as proposed in the consultation document unhelpful and difficult to implement in practice. We conclude that ‘basic care activities’ should not be defined as outcomes.
- However, the CSA is equally clear that the care and support pathway should be outcomes-focused.

#### **Clause 2 (4) Clarifying the meaning of assistance**

2 (4) (a) and subsequent clauses refer to being unable to achieve a specified outcome “without assistance.” The meaning is currently unclear and could lead to inconsistent practice. We believe that guidance should make clear that this includes ‘needs prompting or supervision’. This is especially important for clarity in relation to assistance to take medication discussed above.

CSA members are aware of people who currently receive such support, but who may be at risk of losing it under the new criteria.

#### **Examples**

*Mrs A, aged 76, has care needs which she receives support for. She developed glaucoma and on diagnosis, her care package was increased from one visit to two visits a day. This means that Mrs A has a care worker helping her with eye drops twice a day.*

*Mrs B is 88, lives alone, is registered as blind and is an insulin dependent diabetic. Mrs B was assessed by a community social worker, who identified the risks associated with self-care. A care worker was commissioned to monitor Mrs B’s blood sugar levels and to confirm that Mrs B drew up the correct dose of insulin before Mrs B injected herself. This simple task gave Mrs B confidence. She informed the social worker that it gave herself belief and enabled her to retain her dignity so she could enjoy her day worry free.*

#### **Section 2 (4) (b) – adults and section 3 (6) (b) (i) carers refer to ‘significant pain, distress or anxiety’**

We strongly believe that this should also include ‘significant fatigue’. This is relevant to older people and those with a range of progressive conditions such as MS and Parkinson’s and also people with long-term conditions and carers for whom fatigue increases as they get older.

#### **Recommendations**

- Regarding 2 (4) (a) and subsequent clauses, “unable to achieve (it) without assistance”, it should be clearly spelt out guidance that this includes “needs prompting or supervision”.

- Section 2 (4) (b) for adults and section 3 (6) (b) (i) for carers should be amended to refer to ‘significant pain, *fatigue*, distress or anxiety’

## Specific issues relating to carers

The CSA warmly welcomes provisions in the Care Act requiring local authorities to assess and provide to support to meet carers their eligible needs.

### Significant impact on wellbeing 3 (3) (ii)

As mentioned above in relation to adults, ‘significant impact on well-being’ is only considered in relation to the circumstances set out in Clause 3 (4), not all the circumstances contained in the well-being principle in Section 1 of the Act.<sup>7</sup> In effect, the eligibility criteria are acting as a filter for the wider well-being principle.

### 3 (4) (b) (vii) Access to leisure

The current drafting refers to “access to recreational services”. The CSA believes that this narrows the current wording in the Carers Acts which refers to “leisure”. The word ‘leisure’ is important as it recognises that it is a legitimate need for carers to ‘take time out’ from their caring role, without necessarily engaging in a recreational activity.

#### Recommendation

- The wording should be changed to “leisure activities” as in the current law.

## Young Carers

We welcome the inclusion of clear guidance on whole family approaches and the references in the draft guidance on assessment and eligibility, and prevention that children should not be taking on inappropriate caring roles. This reflects the key principles agreed by Ministers Edward Timpson and Norman Lamb include that – ‘a whole family approach is key when assessing an adult needing care where there are children in the family providing care to the adult or undertaking wider caring responsibilities. The adult’s assessment and eligibility for support should take into account their parenting responsibilities and functioning of the family’.

We need to ensure that the eligibility criteria reflect this commitment from the government.

#### Recommendations

- If all three conditions need to be met for an adult to be eligible for care and support, all three conditions must take into account the impact on the child (their parenting responsibilities and functioning of the family). This raises particular concerns with condition 2.1.(c) which only relates to the impact on the adults wellbeing.
- We welcome the intention that the outcomes consider the caring responsibilities of adult and understand this was intended to consider an adult’s parenting responsibilities. However, the term is ambiguous and can be confused only to relating the children with care and support needs. 2. 2(e) must clearly reference parenting responsibilities in order to avoid any confusion.

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<sup>7</sup> Section 1 (2)

- We welcome the intention to consider the impact on any children in the family which is indicated in 2.4(c) and expanded on in guidance. It is essential to make it clear that in reference to children endangered reflects the guidance elsewhere that a young carer/ child becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.

## CSA comments on the eligibility guidance as currently drafted

### Page 84

- **Paragraph 6.87**

Paragraph below (a) and (b)

'to carry out some of the following basic care activities' should be consistent with the regulations as drafted, so should read 'to carry out some **or all** of the following basic care activities.'

### Page 85

- **Paragraph 6.87 continued**

Clarity is needed on what might constitute 'other comparable care activities,' perhaps achieved through illustrative examples.

'To access necessary facilities or services in the local community including recreational facilities or services' should be changed to 'to access necessary facilities or services in the local community including **medical services; public transport; educational facilities**, and recreational facilities or services' to reflect the additions to the draft eligibility criteria.

- **Paragraph 6.88**

Change 'the local authority should note that there is no hierarchy of needs' to 'the local authority **must** note that there is no hierarchy of needs' to ensure that no one element is prioritised over another.

### Page 87

#### **Case studies of John Taylor**

We understand that the intention of the different case studies of John Taylor may be to illustrate that it is the impact rather than his needs alone which determine eligibility. However, we find this approach quite confusing and have outlined our concerns below.

- **It is very subjective** - the qualifying factor seems to be the socialising aspect in Case study 1 John goes to a chess club and says he can maintain essential relationships despite his severe problems socialising, mentioned under 'Needs'. His needs are found not to be eligible.
- **Both case studies refer to the local authority being "very proactive" in letting John's mother know about carer assessments.** Local authorities already have a legal duty under the Carers Equal Opportunities Act 2004 to inform John's mother of her right to request an assessment. Under the Care Act the local authority has a duty to carry out an assessment of John's mother. Therefore the local authority would be fulfilling their legal duty not being particularly proactive. Without amendment, this suggests both an unambitious and unlawful approach for a local authority to take.
- In Case Study 2, John's needs are the same – the two 'deciding factors' seem to be that although he is still in not in ideal employment, he wants to change this and that the chess club isn't mentioned.

- **Eligibility seems to hinge on how well an individual like John is able to articulate his situation, which for someone for autism will be difficult.**
- **Overall, Case Study 2 does not appear very realistic**, as we believe that many people similar to John who are on the autistic spectrum would not get care.
- In this Case Study 2, the response to John's eligible need is to get connected with an autism social group – this likely to be a voluntary sector community based facility which may not have any statutory footing or funding and **the service may be facing an uncertain future**. However, being autistic, it will be important for John to establish a routine, with some degree of certainty that the service will continue in the longer-term.
- In addition, Case Study 2 says that the local authority will 'make sure' that John gets connected to the autism social group. **It would be helpful to explain how the local authority will do this. It may not be sufficient to rely solely on signposting John**, given that he has severe difficulties socialising and his mother is unlikely to be able to support him as she is getting older. So, although there may not be a cost to the local authority for the autism social group, the local authority may need to pay for support to ensure that John gets to the group under clause 2 (2) (d) in the regulations, accessing necessary facilities or services in the local community.
- For these reasons, the two case studies seem quite confusing. CSA members would be happy to suggest alternatives.
- We also recommend that the guidance includes two case studies outlining different outcomes – one where a person 'is connected to' a community based services and one which results in a more formal care package.

## **Page 88**

### **Paragraph 6.91**

This is a vital part of the guidance and needs to be much clearer on the steps that the local authority should take.

In order to decide which if any needs of the adult are already being met by a carer, the ability of the carer to provide care to the adult should be considered and where a combined adult and carer assessment has not been carried out, the carer's assessment must be considered alongside the adult's needs assessment.

This alignment of the assessments is necessary to determine that there is agreement over what needs the carer is willing and able to meet.

Only where it is agreed between the local authority, the adult and the carer what needs of the adult are already being met can the local authority consider what outstanding needs there are which are currently not being met by a carer and whether these are eligible to be met.

Any needs found to meet the adult's eligibility criteria but which are being met by a carer, and so do not need to be met by the local authority, should be recorded.

The guidance should elaborate on the benefits for the local authority in recording all the eligible needs of a person even if some are being met by a carer. As well as being vital to

address an adult's needs where there is a breakdown in the caring relationship, it will also be important for preparing personal budgets.

A local authority should also be carrying out a carer's assessment either separately or combined with the adult's needs assessments.

**Paragraph 9.95**

The text in the guidance at paragraph 6.87 about the cumulative impact needs to be replicated for carers here.