

**Response from Carers UK to CSCI review of eligibility criteria
May 2008**

1. Introduction

1.1 Carers UK welcomes the opportunity to respond to the CSCI review of eligibility criteria. The Government is currently reviewing its National Strategy for Carers and will launch a revised Strategy later in the spring/early summer. With the forthcoming Carers Strategy and the awaited Green Paper on Long Term Care the CSCI review is very topical.

2. About Carers UK

2.1 Carers UK is the leading organisation representing the views and interests of the six million carers in the UK who care for their frail, disabled or ill family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers UK seeks to end this injustice and will continue to campaign until the true value of carers' contribution to society is recognised and carers receive the practical, financial and emotional support they need.

2.2 Carers UK is an organisation of carers, for carers, with a reach of around 1,300 organisations (including over 100 branches, run by carers) who are in touch with around 1,000 carers each, making our potential reach around 1,300,000 people. With additional local organisations signing up to Carers Week each year, we are also often in contact with another 2,000 or so organisations which means a potential overall reach to nearly 3.5 million people.

2.3 Carers UK run an information and advice service and advise in excess of 18,500 carers and professionals working with carers every year. We also provide training to over 600 professionals each year.

2.4 Carers UK has offices in Wales, Scotland and Northern Ireland and we also run a specific project in London. This response reflects the views of the organisation, UK-wide.

2.5 From 2001 until 2007 Carers UK was the lead partner in a European Social Fund EQUAL programme, Action for Carers and Employment (ACE National) which worked to support the inclusion of carers in training and work. It was a highly innovative partnership which was successful in putting carers and employment issues on the policy agenda, as well as looking at practical solutions to the barriers facing carers who want to work. Its partners included key organisations providing information, advice and guidance on accessing training and work, a leading group of employers (Employers for Carers) and an innovative partnership consisting of key

public, private and not-for-profit social care service providers and policy stakeholders such as regulatory bodies, including CSCI, and trade unions. All relevant government departments, including the Department of Health, the Department for Work and Pensions and the then Department for Trade and Industry were partners. The funding stream has now ended, but partners are committed to continuing their working relationship to take the carers and employment agenda forward.

3. General comments

- 3.1 Our response below focuses on the review's questions mainly from the perspective of carers. However, to put this in context we outline here some short introductory comments firstly about who we mean by carers and, secondly, about the issue of eligibility criteria within the wider problems of the social care system.

Who do we mean by carers?

- 3.2 Our definition of carers, which is also accepted and used by the Department of Health, is people who "look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid." Carers are an often hidden but very substantial part of our population, constituting around 6 million people in the UK, i.e. 10% of the total population and approximately 12% of the adult population. With the number of people aged 85+ predicted to increase by over 900,000 in 2025 (*GAD 2003-based population projections, Crown Copyright*), and part of this longer life span likely to include more years in poor health, the number of carers is also set to rise, with an estimated additional 3 million required by 2034 (*More than a Job – Working Carers: evidence from the 2001 Census*).
- 3.3 The vast majority of care takes place at home and a very substantial part of this is provided by unpaid carers. A recent report by Carers UK, published in September 2007, revealed that the value of this unpaid care has increased to a staggering **£87 billion** worth a year – more than the annual running cost of the NHS which stood at £82 billion in the year 2006-7. Public policy therefore cannot look at people in isolation but must look within the context of their families and relationships. Our ageing population will therefore have an impact both on the formal care system and on these caring relationships between families and friends.

The issue of eligibility criteria within the wider social care system

- 3.4 As an initial comment, we do not believe that the specific concerns around eligibility criteria can be easily disentangled from wider problems with the social care system. Key questions need to be answered, including, firstly, what is the social care system for? (i.e. is it to promote independence and support to all families who need it or to act primarily as a safety net when private arrangements fall through?). Other questions are how should the system be funded, and what sort of services should it be delivering? We welcome the fact that CSCI are mindful of the wider changes taking place in social care and are looking to make recommendations which will survive further change.
- 3.5 We appreciate that whatever system we have there will need to be decisions about

who can receive state funding. However we but feel that at present the social care system is geared towards reducing budgets. Too often, therefore, councils' overriding ambition seems to be to keep people out of the system.

3.6 Carers mainly have contact with the social care system because of the support or Services that the person they care for receives. Carers are often very involved with the process of assessment, supporting decisions about services and ensuring that the services are delivered appropriately. In some cases, carers also control direct payments on behalf of the person they care for. In these cases the role they play is formalised.

3.7 However some carers are also entitled to services in their own right. In this respect the FACS guidance covers them specifically, although we believe that awareness of this is low. This review must therefore understand the impact of FACS on carers both as individual recipients of care services and as people who are impacted on by the services which the person they care for receives.

4. Questions from CSCI:

Q.1 Is the current Fair Access to Care Services (FACS) system appropriate in principle? What principles should underpin eligibility for publicly funded social care?

4.1 We believe that in most areas, the intention behind the FACS guidance is sound and makes appropriate judgements about how families should be supported by local authorities. When it was introduced it was welcomed by Carers UK and others as we believed it would bring an end to arbitrary decision making and inconsistency.

4.2 However we believe there are many areas where FACS is not being implemented properly and that this is the cause of many of the problems highlighted by CSCI and others (please see the section below for specific points).

4.3 With regard to what principles should underpin eligibility for publicly funded social care, we believe that these should be as follows:

- **Access to services should be transparent and there should be a coherent system between privately and publicly funded services.**

4.4 We believe there are a number of areas where FACS is not being used as a basis for decisions about services, e.g.

- Universal services, especially those contracted to the voluntary sector. Councils feel they do not necessarily get the recognition for these services. However efforts must be made to ensure access to these services is allocated transparently and consistently. We would also pose the question of whether there is a way of bringing them into FACS?
- We are concerned that some councils set their eligibility levels at a high level in order to give them maximum discretion about the allocation of services and to appear to be keeping control of costs.
- We have further concerns about how eligibility criteria will develop in future social care programmes, particularly in the Individual Budgets pilots and in other

authorities who are not part of the pilots but are using individual budgets. A system of individual budgets makes much more use of self-assessment in order to allocate a budget through a Resource Allocation System. This is an area we intend to do more work on, but our initial concern is that this system is moving away from the established legal framework of Community Care Assessments or Carers Assessments. It is our view that assessments are critically important for both carers and the people they care for and that a good assessment can be a genuinely life changing experience for a family. Equally, a poor assessment (or long delays in getting an assessment) can leave families confused, unsupported and sceptical of the value of services. We say more about the issue individual budgets in response to CSCI's later question on this issue.

- **The decision about needs and means should be separated**

4.5 We believe that recent trends show that councils are confusing the assessment of people's needs with that of their means. In a period of tight budgets, rather than maintain the level of service and the number of people supported, but asking them to contribute more financially (which of course has its own equity considerations), councils are withdrawing services and leaving people entirely to their own devices. We believe this is not the policy intention behind FACS but that this needs to be considered by this review.

4.6 A firm principle of any system of eligibility should be that it separates needs and means – in principle and in practice. This means it should be attractive and welcoming enough for those who know they will be required to self fund to still enter the system. What we ask them to contribute financially is a separate decision to be made once their needs have been assessed.

- **The system should recognise the contribution of carers but not take advantage of the care they provide in order to provide fewer formal services.**
- **Value for money for the tax payer should not mean reducing budgets for services or cutting corners. But it does mean using cost-benefit analysis and focusing on prevention.**
- **FACS should facilitate links with other local authority services and help meet broader corporate objectives.**

4.7 At present FACS seems disjointed from the corporate aims of local authorities and the strategic goals that many of them have to support independence, choice and a good quality of life for disabled and elderly people, as part of their general objectives for their communities.

Q.2 Does the FACS system work in practice? If not, why not?

4.8 When FACS was introduced, it was intended that all four bands would be largely in use. At a time when this is overwhelmingly not the case, a thorough reassessment is needed. People need to have confidence in the system and know what they are likely to get. They also need to be able to challenge the system.

- 4.9 A consistent problem is that FACS often talks about what councils 'should' do rather than saying they 'must' do. **This particularly applies to carers where there is no duty to provide services, only a power.** Whilst respecting the principles of local democracy and decision-making, there is concern about these principles being ignored on a widespread basis.
- 4.10 The biggest problem that families face regarding eligibility criteria is where they need services (this being something they are well able to judge for themselves) but are not considered a high enough priority by their local authority to receive state funded support. In practice, these families are still covered by FACS (as is explained in the section '**Supporting individuals whose needs are not eligible for help**', particularly paragraph 68) and the local authority should help them find appropriate services which they will have to pay for themselves. Of course, the wording in Paragraph 68 does say that councils 'should' help people to find the relevant organisations, rather than they 'must'. However it is our belief that very few councils are following this piece of the guidance and introducing families to appropriate services.
- 4.11 As CSCI pointed out in *The state of social care 2006-07*, many people are lost to the system. Councils are not fulfilling the role of **assessing everyone regardless of means**, which paragraph 70 makes clear they should be. Clearly people are being diverted by the knowledge that they are not likely to be eligible for state funded care.
- 4.12 We believe that councils should have stronger responsibilities for **the assessment of everyone who requests it**, along with a stronger care management role. At present the lack of information and understanding about the private care market means that, even where these people have the resources to pay for care, they are not able to access it. Others could not afford private care anyway. By not being aware of these people and ensuring they have the support they need, there is a risk that they will re-enter the system at a later date, either as critical cases requiring social care services, or as patients in the National Health Service.
- 4.13 **We believe that FACS is not at all well understood in terms of carers** especially by frontline practitioners. The interaction between FACS and the carers legislation is complex and there are several types of problems here. Firstly, some councils appear to believe that FACS only relates to service users, while others do not seem to understand that it is Policy Guidance and therefore mandatory. Some councils are failing to collect adequate information about carers at the contact assessment/screening stage. There also appears to be a fundamental misunderstanding of the discretion to use carers' services, i.e. there is a duty to address carers' eligible needs but discretion about whether to meet these through carers' services instead of by community care services. Some practitioners appear to be confusing this, apparently believing that the discretion is about whether to help carers at all. Lack of understanding by practitioners is also leading to inconsistent outcomes for carers, with many being referred on to other sources of help or advice.
- 4.14 Another major problem for carers is **inappropriate assumptions** being made about their willingness to care. This can lead to too low an assessment of the level of need and risk.
- 4.15 Although the **Carer's Assessment** is supposed to take these issues into account,

too few people are receiving an assessment, and the follow up analysis on the family's support needs as a whole is not taking place. The system is too process-driven and services are not being designed and allocated based on the difference they will make to people's quality of life. Local authorities need to be more effective at measuring this.

- 4.16 **Variations between local authorities** with regard to carers assessments also cause a lot distress and confusion for families. If people move to another local authority area it is ridiculous that the whole process must be started again. There should be a system where assessments can be carried over. Information should be recorded in such a way that another local authority can make decisions based on the information in the assessment. This would be less stressful for families and would also reduce some of the bureaucracy and the waste of resources.
- 4.17 But ultimately, there should be local decision making and accountability. There needs to be a **communications strategy** to ensure that people know where decisions are made and how to influence them. Social care should be a bigger issue in local elections. Simplifying the rules will make this more possible.
- 4.18 Other areas where the FACS system is not being implemented properly include Paragraph 69: **planning for emergencies**. Carers UK highlighted the problems in our 'Back me up' campaign and Government had to find specific funding to make it happen. However, the FACS guidance here is still not being implemented properly.

Q.3 What changes would you put in place:

- **in the short term, if the overall social care system remained broadly the same?**
- 4.19 It is helpful to have a national framework such as FACS otherwise there would simply be a "post code lottery". However, unfortunately, because it is not being enforced or communicated properly, the system does not seem to have prevented such a post code lottery in practice. We therefore believe that as a priority in the short term FACS must be:
- properly **monitored and enforced** by inspectorates and by local authorities themselves
 - properly **communicated and understood** by local authorities and frontline practitioners
- 4.20 We also believe that certain elements of FACS need to be clearly restated and enhanced especially:
- that its status is Policy Guidance and that it is therefore **mandatory**
 - that it relates to **carers as well as service users**. This must be addressed via Government guidance, local procedural guidance and staff training
 - clearer guidance and enforcement at local authority level about collecting adequate information about carers at the **contact assessment/screening** stage
 - clearer guidance and enforcement about the **discretion to use carers' services**
 - more support for people (and their carers) who are deemed **ineligible** to receive state funded services

- guidance on, and establishment of, **feedback systems** asking about what happened when people (users and carers) have been referred to voluntary organisations
- responsibilities for the **assessment of everyone** who requests it, along with a stronger care management role
- the launch of the new **National Carers Strategy** provides a good opportunity to raise awareness of the above issues

4.21 Whatever system of rationing is used, we believe **advocacy** is vitally important.

With such a large number of decisions being made, there need to be avenues for challenging them which individuals can pursue and which will be easy to access and low cost. Better systems of advocacy would help counter the perception that local authorities are not supportive and are trying to restrict access to services. We do not believe this is the intention of most social workers, but they are forced into a gate-keeper role by a lack of resources.

4.22 FACS needs to reflect the important links between local authorities and **other service providers**. For example, primary care services (notably PCTs and GPs) need to be engaged more effectively in identifying carers' needs if carers are to be supported properly.

Q.3 (cont'd)

- **anticipating the transformation of social care in implementing Putting People First and the expectation that personal budgets and self-directed support become mainstream? and**
- **if there were to be a radically new approach to the funding of social care?**

4.23 In all future developments carers must be **fully involved** in the development of support services for them whether this is for eligibility criteria and assessments, personal budgets or other forms of self-directed support. For example, it is particularly important in the roll out of personal budgets that assumptions are not made that carers will automatically manage these but, rather, they should be given information and support to make their own choices. If **choice not force** is used, and people have the proper backup to take on these responsibilities, it is more likely they will do so successfully and benefit from having greater control over their lives.

4.24 Carers' rights and needs must be addressed consistently (and must not be eroded) across the range of the above initiatives. For example, **eligibility criteria for personal budgets** must take account of the carer's needs and any risk to the carer (including risk of social exclusion) as well as to the service user. Specifically, the Resource Allocation System (RAS) for personal budgets should reflect these needs and explicitly recognise the rights of carers to choose whether or not to care. Where people do choose to care, the RAS should make specific allocations to support carers, both in their caring role and to promote their social inclusion, for example, there should be provision for breaks and support to have a life outside caring. It is important that any new local eligibility criteria are accessible for, and developed with, carers.

4.24 We believe that the social care system should have **universal elements** –

specifically information (already provided by local authorities to varying degrees), case management and advocacy.

- 4.26 Social care services should be **provided to all those who need and want them** (whether or not, according to their financial circumstances, people may have to pay for these services). This would ensure that there would be coherence between publicly and privately funded services. In particular, there should be more information and support available – and more transparency about what sort of help is available – for families who are ‘self funders’, i.e. who are not deemed as eligible for state-funded care. As has been outlined above, these families are referred to in FACS but there needs to be clearer guidance (or the guidance needs to be better enforced) that local authorities must help them find appropriate services. There should be a financial assessment and the required contribution may include some of the costs of the assessment and care management services.
- 4.25 Local authorities should provide a greater **case management** role which would help ensure the above greater coherence between publicly and privately funded services. This role should organise services from the private, voluntary sectors as well as the public sector, and be able to utilise other council services and health services.
- 4.26 In order to achieve a more ‘joined up’ social care system the issue of **perverse incentives** caused by different financial systems needs to be tackled. As has been increasingly recognised, this is the cause in practice of many of the problems in accessing services experienced by users and carers. Most notably, lack of co-ordination between social care and health systems, for example around hospital discharges and admissions, can cause real practical problems for carers and families. The only really effective way of eradicating this problem is eradicating the clash of interests between the funding systems by **pooling budgets** for such services.
- 4.27 In the meantime and, along with this, there should also be greater use of **joint assessments and care planning** between health and social care.
- 4.28 More long term, the social care system – along with the health service - needs to move towards a greater emphasis on **illness prevention and health promotion** with a greater focus on early intervention and identification of needs. At present the system is really more geared up to picking up the pieces when things go wrong, and even here it is unable to meet current needs. There should also be more triggers and incentives for the health service to pick up and respond to their carers’ needs, both in regard to their own health and to the support that they may need in their caring role. We have outlined our thoughts about this in more detail in our response to Lord Darzi’s NHS Next Stage Review.
- 4.29 In line with this, eligibility criteria in the future this might be linked, both for health and social care, to the positive outcomes identified in “Our Health Our Care Our Say”.

5. Concluding comments

- 5.1 In this response we have sought to focus on the review’s questions mainly from the perspective of carers while also putting this in the context of the wider problems of the social care system. We have outlined some brief general comments (Section 3), and, in response to CSCI’s questions (Section 4), we have outlined our views on the

current FACS systems and the principles we believe should underpin eligibility for social care. We have also commented on why we think the current FACS system is not working in practice and, finally, what changes we think should be put in place. There are of course many other issues relating to eligibility criteria and the wider challenges of the social care system and potential ways in which these could be addressed. We would be happy to provide any additional information that CSCI may require.

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