



**Consumer
Focus**
Campaigning for a fair deal

Consumer Focus response to the Department of Health consultation: Shaping the future of care together

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About Consumer Focus

Consumer Focus is a statutory body that champions the needs of consumers across England, Wales, and Scotland and, for postal services, Northern Ireland.

We operate across the whole of the economy, persuading businesses and public services to put consumers at the heart of what they do. Our public services work seeks to improve provision by promoting high quality engagement in design and delivery of services.

Consumer Focus has the power to take action where markets are failing consumers and to ensure a fair deal for all – especially people who are vulnerable and disadvantaged.

We want to see consumers as central to business and Government decision-making, and we work at European level too, to make sure consumers' needs are heard in Brussels.

We don't just draw attention to problems – we use a strong evidence base and work with a range of organisations to champion creative solutions that improve consumers' lives.

Shaping the Future of Care Together: Department of Health consultation on a new vision for care and support

Response from Consumer Focus

1. Introduction and executive summary

The Government's Green Paper 'Shaping the Future of Care Together' aims to set out a vision for a new care and support system in England. The basis for the current care system was laid in the 1940s and needs to be brought into line with people's needs in the 21st century. The Green Paper seeks to outline a system that is fairer, simpler and more affordable for everyone. It marks the beginning of what Government has called a Big Care Debate which involves making some big decisions and reaching agreement across society on the right way forward¹.

Summary

Consumer Focus welcomes the Green Paper, 'Shaping the Future of Care Together'. Action is urgently needed to sustain and improve care and support services for adults in England. It is essential that consumers' interests are secured in any changes to reform these services, particularly those of consumers who are in vulnerable circumstances. Consumer Focus, and its predecessor organisations, have had a long-running interest in, and duty to, address the needs and interests of people who are at risk of disadvantage and/or vulnerability. Vital issues such as the accessibility, quality and safety of social care services are of major concern in this regard.

The Green Paper sets out a number of proposals for changes in arrangements for care and support services, but there are some serious gaps which we urge the Government to address in the subsequent White Paper. In particular:

- The focus on older people means there is insufficient detail about how the new system would serve the needs of all who require care services – including disabled people, people with mental health problems or a long term medical condition, and people with substantial caring responsibilities
- The proposed national care system is a significant step forward but by leaving implementation to the discretion of local authorities the issue of fairness remains unresolved
- The lack of enforceable entitlement rights as well as access to information and support that would enable consumers to make informed choices about their care further undermines Government's aim to be simpler and fairer
- The funding options do not provide sufficient detail about how they would work. This makes it impossible for people to see what they will have to pay

¹ Shaping the Future of Care Together, Department of Health, 2009

themselves, what they can expect the Government to pay, or to judge which is the fairest. Detailed, costed proposals are required before initiating a debate on a new funding mechanism and whether it is fair

- Achieving a national care system depends on an effectively integrated approach to healthcare, housing and social care services, including community equipment services but it is not yet clear how this will come about. Government will need to develop explicit proposals to demonstrate how the different branches will be fully linked together
- It will be essential to clarify the remit, powers and duties of the intended overview body for care and support services. We also strongly recommend that the body engages directly with consumers to ensure an ongoing dialogue about the effectiveness of the new system
- Government should adopt the principles listed in section 2 to guide the strategy for developing and implementing a new care system. These principles include access, safety, accountability, redress, fairness, and evaluation as well as consumer empowerment

We look forward to seeing firmer proposals that address these and other concerns which we discuss in more detail in our response.

2. Shaping the Future of Care Together: Consumer Focus response

Introduction

Consumer Focus welcomes the Green Paper, ‘Shaping the Future of Care Together’ as action is urgently needed to sustain and improve care and support services for adults in England. It is essential that consumers’ interests are secured in any changes to reform these services, particularly those of consumers who are in vulnerable circumstances. Consumer Focus and its predecessor bodies² have had a long-running interest in, and duty to, address the needs and interests of people who are at risk of disadvantage and/or vulnerability. Vital issues such as the accessibility, quality and safety of social care services are of major concern in this regard.

However, although the Green Paper sets out a number of proposals for changes in arrangements for care and support services, there are some serious flaws or omissions, which we urge the Government to address in the subsequent White Paper. In particular, while the Paper correctly recognises that the needs of older people must be addressed in current and future service planning and delivery, the proposals need to pay explicit attention as well to the needs of others who are likely to require these services. This includes disabled people, people with mental health problems, those with learning disabilities, people with substantial caring responsibilities, and others such as people with a limiting long term medical condition.

Overall, the Paper is aspirational in its approach rather than specific, and we look forward to seeing more concrete proposals in any subsequent White Paper. Overall, the critical missing element in the Green Paper concerns the lack of enforceable entitlement rights to care services based on people’s needs assessments. In addition, the proposals need to be more explicit about the need for a joined-up and integrated approach to healthcare, housing and social care services, and also community equipment services.

As the Green Paper makes clear, the old ‘one size fits all’ approach to social care, and much health-related care, is continuing to be replaced or overtaken by a more person-

² The National Consumer Council, Postwatch and energywatch

centred model of care and support, frequently associated, with notions of consumer choice. In addition, the Government proposes the continuation, in one form or another, of co-payments for services and equipment. This can place patients/clients in the role of being a consumer in a market, spending their own money for care. Consumer Focus recognises that conventional notions of consumer choice in the marketplace do not always apply in the care and support sectors, but the importance, for instance, of consumers being able to make an informed choice (even if money is not exchanged) clearly matters. This is a crucial issue and the Government must address it properly – at the very least it should acknowledge publicly that making meaningful choices in what can be a quite complex sector requires more than rhetorical statements.

Building blocks for the new care system

Using a set of principles to develop proposals for the national care system will help to ensure that the fundamental needs of consumers, service users and carers are met. The planning, commissioning, provision and delivery of care and support services should be based on these principles, which include the following:

- **Accessibility:** there should be universal affordable access to good quality care and support services; consumers should be able to negotiate easily their way through the services and have a range of means of making contact with providers
- **Safety:** rigorous and appropriate risk assessments must be applied, customers must be provided with the means of raising any and all matters relating to their safety, health and wellbeing, and getting their concerns resolved
- **Accountability and transparency:** it should be clear who is ultimately responsible for the provision of a service; key information about the quality of services should be publicly available, as should clear and easy to understand information about the effectiveness of services, measured by outcomes for consumers
- **Complaints and redress:** consumers should have easy access to fair and robust complaint handling processes, and easy access to independent and fair redress systems for unresolved complaints. Information on patterns, volumes and the nature of complaints should be routinely published and made widely and easily available
- **Consumer support and empowerment:** consumers should have easy access to clear and comprehensible information about what services are available and any eligibility criteria; consumers should have access to free and independent advocacy support if they need help in sorting out problems. They should also be fully engaged in the ensuring the design and delivery of services is effective in meeting the needs of people who use care and support services
- **Efficiency:** care and support services should operate efficiently and effectively to provide high quality value for money services to individual consumers and to consumers in general
- **Fairness:** policies and practices in care and support services should not operate unfairly or discriminate against any consumers, including those in vulnerable situations. This includes ensuring that consumers in vulnerable circumstances are not treated unfairly because of failures to consider and meet their needs, for instance, by failing to provide information in different forms or languages or through the absence of assistance for people with learning difficulties
- **Monitoring and evaluation:** this includes the use of quality assurance systems in the design and delivery of services, and ensuring that consumers' experiences of services are sought when services are evaluated

3. What's the problem?

The Green Paper rightly points out that the current care and support arrangements were developed over many years, and have often changed as well over time. This has led to fragmented, and sometimes contradictory, sets of rules and entitlements, and to the existence of unjustifiable postcode lotteries. Governments have attempted on successive occasions to make care and support systems more coherent, comprehensive, and comprehensible but, as the Paper acknowledges, much more needs to be done.

The need for a fully comprehensive approach

In any subsequent White Paper, we would like to see a much more nuanced and substantive account of the many contradictions and disjunctures experienced by people using social care, housing support, and welfare benefits to provide them with care and support. Consumer Focus does not believe that the Green Paper provided an adequate account. This is an essential starting point in understanding what needs to be changed and in what ways.

The Green Paper correctly recognises that the needs of older people must be addressed in current and future service planning and delivery. However the proposals also need to pay explicit attention to the needs of others who are likely to require these services. Future policy-making and proposals, including any White Paper, must incorporate a detailed and informed assessment of the wide range of needs of people who may require care and support services. As well as older people, these include disabled people, people with mental health problems, those with learning disabilities, and others such as people with a limiting long term medical condition. Full account must also be taken of the needs and interests of people with substantial caring responsibilities.

The Green Paper rightly emphasises the importance of dignity and the quality of life. However, a fundamental issue which remains unresolved or unclear is what constitutes health-related services and social care services. For example, despite all of the previous 'joined-up' initiatives, a person needing help with having a bath at home is not likely to have to pay for the service if it is deemed to be therapeutic in health terms, but they are likely to have to pay if the service is deemed to be part of 'normal living'. These are issues which very much affect people's dignity and quality of life, and also underline the need for a joined-up approach to support and care services.

In addition, if services are to be fully joined-up, crucial aspects such as housing need to be considered, especially as people's housing circumstances may well affect their need for care and support services. Supported accommodation (anything from 'sheltered housing' to assisted living facilities) is very unevenly spread across England, and net costs for the consumer vary widely. Consequently the opportunities for people to live independently and affordably are often subject to the 'postcode lottery' problem and this has implications for social care services.

Moreover, much more attention needs to be paid to the, quite common, situations where people may, on a long term, short term or episodic basis require a number of different services. For example someone who has had a stroke may not only need healthcare following discharge from hospital but also assistance from a falls prevention service.

The Green Paper also fails to pay sufficient attention to related services, such as access to community equipment. For example, delays in assessing and providing community equipment like aids in the home can adversely affect a person's rehabilitation, their self-confidence, and ability to live independently with a good quality of life and may lead them to require a higher level of support as a consequence.

The Green Paper does not properly tackle the role of benefits income and rules and how they affect consumers' lives, their needs, and their interactions with current social care eligibility means testing arrangements. For a start, there continues to be a significant amount of under claiming by people entitled to benefits and it is essential to ascertain the extent to which this is caused by the sheer complexity of the benefits/tax credits system. This 'system' signally fails to match up to basic consumer principles such as transparency. Also, some of the rules in the system can effectively impose financial penalties or other unintended consequences, particularly but not exclusively at certain key points in people's lives, such as when trying to get back into paid work, for example:

'Income support paid my rent, school meals and health benefits. When I started working I didn't lose the exemption card for health because I don't earn enough. When my son was in the hospital I didn't get income for meals and transportation. If you work you don't get that.'

'Working tax credit is less than £10 a week. I have been offered a full-time job but I declined it because if I come to work five days a week I will increase my wages and I will get nothing from the WTC [working tax credit] and also from the CTC (child Tax Credit).'

'I applied for WTC and they said that I was not eligible because I did not work 30 hours per week. When you are looking after a child with a problem, they should be helping you. I was shocked.'

(Examples are taken from 'Interact: benefits, tax credits and moving into work', Community Links, Low Incomes Tax Reform Group, and Child Poverty Action Group, December 2007)

These outline examples are intended to illustrate why it is so important for reform of care and support services to be grounded in the reality of consumers' circumstances and expectations, and not on general aspirations. The Green Paper includes quotes from organisations involved in prior, related, consultations which emphasise that this proposed process of reform may be a once in a generation opportunity. If that is so, then widespread consumer involvement is essential to inform policy-making and decisions (for instance as emphasised by the Department of Health in relation to people with learning disabilities in the report 'Nothing about us without us', DH 2001). It also underlines why it is essential that the Green Paper's shortcomings are addressed properly in any subsequent White Paper.

The need for a proper evidence base

Funding needs

One of the main propositions in the Green Paper is that the current system of care and support is unsustainable. In particular there is a focus on the 'ageing population' in England and on an assumption that there will be a growing number of younger adults with care and support needs in the future. It also maintains that people's expectations of care are changing. The Green Paper argues that these factors will make the care and support 'system' financially unsustainable.

Consumer Focus regards it as imperative that the Government is much more specific about what financial shortfalls it envisages, and in what sectors or sub-sectors based on robust and rigorous analysis. For example, does it simply envisage that services required by older people with dementias, and their families/carers, will rise in cost pro rata as projected numbers of older people increase? Or has the Department of Health examined ways in which early and effective interventions might reduce the impact of dementia on the individual and their family; something which could reduce the rate of increase in costs?

Another question is whether it is just assumed that the rising number of adults with learning disabilities, including many with Autistic Spectrum Disorders, will incur a pro rata increase in service needs and costs? Or has the Government examined whether there are more (cost) effective ways of providing supported accommodation and pathways into paid work?

In addition, is it simply envisaged that the amount of domiciliary care services required will rise in line with demographic change? Or has it been considered whether a reconfiguration of services, for instance by introducing early intervention services, rather than relying solely in supplying such services only to those with very high levels of need, might tend to bring down costs in the longer term?

In short, before proposing major changes in broad funding arrangements for care and support, much more clarity is needed about the evidence base upon which any changes are based. This includes the size of projected shortfalls, the basis on which such calculations have been made, and whether service reconfigurations or more innovative approaches to service design and delivery might deliver more for less.

The reality of people's needs

It is also disconcerting that the Green Paper tends to assume that there are a number of 'groups' of people who do or will require care and support. Of course people with some types of condition or disability are quite likely to require ongoing support for a considerable period of time. However, for many others, support may only be required for a short period or perhaps episodically. For example some people following a stroke or other acquired brain injury might need a high level of support for a number of weeks or months, but then require far less. Some physical impairments, for example, tend to fluctuate in their severity and so people experiencing these may only need support from time to time; this can also be the case for many types of mental health problem. Carers' support needs too can vary over time, depending on both the situation of the person being cared for and the carer's own physical and mental health.

The right support for the right period, provided in a timely and effective way, is commonly acknowledged to provide not only the most cost effective way of delivering many services, but also to provide the best outcomes for people.

Any subsequent White Paper and policy proposals should seek to set out a more nuanced and reflexive understanding of people's needs and circumstances. This should be done by drawing on research evidence, and by gaining much more firsthand knowledge from consumers about their needs and experiences.

The extra costs of disability

There is little or no recognition in the Green Paper of the impact on individuals and households of struggling to meet the extra costs of disability. This can add about 25 per cent to a household's costs, especially in the many low income households. Yet it is well known that people with disabilities, and those with limiting long term medical conditions, are at higher risk of living in poverty than many others in society. For example disabled adults aged 25 to retirement age are twice as likely as others to live in low income households, and 55 per cent of families with disabled children live at the margins of poverty (more than four times the percentage of all households)³. Also, a high proportion of carers are known to experience financial difficulties.

³ Disability poverty in the UK, Leonard Cheshire, 2008

It could be argued that many individuals and households who require and/or have used care and support services have, in effect, borne at least some of the costs associated with their needs – some of them for many years and not just in terms of disposable income, but also savings, pensions, etc. For example:

- the Leonard Cheshire report highlighted that nearly a half of all disabled people have no savings at all, compared with 12 per cent among the general population
- the New Policy Institute highlights the fact that the poverty rate for disabled adults of working age is twice that of non-disabled adults⁴
- the Government's Office for Disability estimates that the percentage of children living in income poverty in families with disabled children, regardless of adult disability, is 38 per cent, compared to 28 per cent living in families where no-one is disabled⁵

The apparent lack of recognition that a substantial number of people have and are suffering financially in this way is not only disturbing but it also leaves a large flaw in the Government's discussion about how to pay for services. These matters are also very relevant when considering some consultees' previous comments about a perceived unfairness (namely, those who have savings pay, those who have not saved do not pay).

This important issue should be urgently factored into any future consideration of the means of paying for care and support services. It also underlines the need for policy-making in this area to be properly grounded in the reality of consumers' circumstances.

4. A national care service

A national care service, alongside a new national needs assessment, form two of the key proposals in the Green Paper.

Consumer Focus welcomes the idea of a national care and support service. Anything which might help consumers to avoid having to deal with multiple agencies (each with their own rules, practices and procedures) often at a time of difficulty and distress would be a great step forward.

The scope of services

However, the Government must be clearer about the scope of its national care service as it is difficult to discern what, if any, concrete proposals are likely to emerge. For example what exactly would such a service cover? The general tone of the Paper implies that health, social care, housing, and benefits might be included. However, the proposals are not sufficiently specific. It is also odd that in a 136 page document no mention is made, for instance, of statutory and non-statutory drug and alcohol abuse services, or of specialist dementia services.

It is difficult to know whether the Green Paper and any subsequent White Paper presages significant changes in the many current policies aimed at promoting or ensuring joined-up partnership working, with or without pooled budgets, etc. across different services. If no changes are envisaged, then it is difficult to understand how a 'national care service' can be anything more than a form of rhetorical shorthand.

Consequently Consumer Focus urges the Government to make clear proposals on any further developments envisaged for further 'joining up' of service planning and delivery. One key issue which requires attention is where those with multiple needs in the short or

⁴ Disabled people, poverty and the labour market, Guy Plamer, New Policy Institute 2008 See <http://www.poverty.org.uk/summary/disability.htm>

⁵ Annual report, Office for disability, 2008

longer term fall through gaps because current care systems are designed around homogeneous groups⁶.

Another particular concern is where any health and health-related services might fit into a national care service, not least because most of these services are provided free at the point of delivery, or are provided free for those who are eligible, eg prescriptions for over-60s. This is in contrast to the means-testing framework applied to most social care services. Another example is foot care and podiatry, some of which is provided free through the NHS, some of which consumers are expected to pay for privately, even if their GP recommends a particular clinic or course.

So it is essential that the Government produces a comprehensive, and comprehensible, guide for consumers about what constitutes a healthcare service, and whether and under what circumstances the consumer is expected to pay, in part or in full.

Similarly, much more detail needs to be provided about how the configuration of a national care service might reduce or eliminate regional and local disparities. This is not just in terms of costs to the consumer, but also in terms of the quality, types and amount of service provision available. The Green Paper's heavy emphasis on ways of paying for care and support in the future needs to be matched by a proper consideration of what services consumers should have a right to access and under what circumstances.

Also, while it seems likely from the Paper that most or all of the responsibility for commissioning care services will fall to local authorities, and in many ways this is sensible, for example because local knowledge of needs is valuable, much more needs to be said by Government about what, if any, means might be proposed to avoid the continuation of 'postcode lotteries' in the quantity and quality of service provision.

Navigating through services

There needs to be greater acknowledgement of the current complexity of what might be assumed to come within a national care service and therefore the difficulties which can face consumers. They may need to find their way around the Department for Work and Pensions' (DWP) benefits system, the Social Fund, HM Revenue and Customs for tax credits, the local authority for Council Tax or Housing Benefit, Jobcentre Plus or the Benefits Enquiry Line for Disability Living Allowance, plus the plethora of health and social care bodies and practitioners (including, for instance dietician services, speech and language therapy, occupational therapy and physiotherapy services) and housing authorities. In addition, consumers of care and support services may also need to know whether various contracted-out or jointly-commissioned services might be of assistance to them, such as a mental health rehabilitation service, a falls prevention scheme, or a short term emergency support team.

Trying to find out and navigate through the benefits system itself can be tough, for example the Disability Alliance's annual handbook runs to nearly 300 pages, daunting even when one is well and unstressed. Trying to discover and accurately map all of the other care and support services can be equally daunting. Also, some services are run through partnership schemes, involving for example the local authority, a local or national charity, and perhaps a private sector organisation or social enterprise. In addition there is an, often complex and overlapping, web of eligibility rules and charging systems.

⁶ For example, see A four-point manifesto for tackling multiple needs and exclusions, Making Every Adult Matter, 2009

Consequently a comprehensive and coherent national care service would have to include, as a central element, a competent, easy to access and free advice and advocacy function which could encompass everything from 'signposting' to assistance in making complaints and obtaining redress. It would be important, as far as is practicable, to avoid the necessity for the consumer to have to make multiple contacts in order to find out about their rights, the nature and purpose of local services, the likelihood of their eligibility. The need to address this issue has already been acknowledged, albeit in a limited way, by the DWP in its 'Tell Us Once' pilot trials.

Complaints, redress and personal information

The Government should set out clear and concrete proposals to ensure that there are robust and fair complaint handling and redress systems. In particular, consumers should be confident that complaints will be considered speedily, fairly and effectively and that they have easy access to independent and fair redress systems without having to make multiple contacts and applications. Consumer Focus believes it essential that a single 'national care service' should as far as possible offer a single point of contact for service users and carers who wish to make a complaint. Many consumers who need to use care and support services are likely to be vulnerable, so a service failure could have significant personal consequences and then having to cope with unclear or complicated complaints handling processes adds further to stress and distress.

Secondly, care needs to be taken to give consumers accurate help and advice with respect to complaints – such as helping to clarify whether a person's complaint is really about the competence or standard of professional practise of a member of staff, or perhaps the practices of a particular organisation. Similarly with respect to matters such as inability to access required services, or to the accuracy or adequacy of care and support assessments. Proper consideration should also be given to the position of consumers whose service is provided through multi-agency partnership schemes so that there are clear lines of responsibility established. Information about lines of responsibility and accountability should be easily available to consumers.

There are potential benefits for consumers in relevant agencies being able to share information about them. This would mean that professionals are fully in the picture and avoid consumers having to repeatedly provide information to different organisations. However, a national care system will need to employ a clear and robust set of rules about the sharing of personal data between services and agencies and clear statements about consumers' rights to accept or object to the sharing of personal information. In addition, consumers should have the right to view this information and be able to access easy-to-use mechanisms to challenge information about themselves which they regard as inaccurate or inadequate.

5. Assessment and consumers' rights

Assessment of needs

Consumer Focus welcomes the proposal for consumers to have an assessment of need which can be used anywhere in England, rather than having to have a new assessment if they move into another local authority area.

We are, however, concerned about the wording of the proposal, namely that people '*...will have the right to have your care needs assessed in the same way*'. A consumer having their needs assessed in the same way does not in itself guarantee a common understanding of an existing needs assessment between local authorities. The wording in the Green Paper needs to be clarified in any subsequent White Paper in order to avoid the possibility of confusion, for the consumer, staff and agencies alike.

A truly portable needs assessment implies that a reasonably equivalent care and support service, or set of services, will be provided to a person anywhere in the country, even if the precise configuration or arrangement differs because of local commissioning decisions and/or the type of service provision available.

Consequently consumers need to be assured that, in broad terms, they are guaranteed not to 'lose out' because their portable needs assessment is viewed differently by staff in different localities. Existing equalities duties required of public bodies and their agencies should in theory already guarantee the end of discrimination arising from this issue, but Government should ensure that in any subsequent White Paper this legal duty is highlighted. Also, there should be a clear recognition that consumers who believe that they have suffered, or will suffer, as a result of moving have a right to make a complaint and to have their complaints dealt with fairly and quickly.

The Green Paper is also less than clear about what, if anything, the Government intends to do to promote or ensure a 'joined up' needs assessment for all adults – to match the proposed national care and support service for England. Consumer Focus understands that some needs assessment processes require specialist rather than 'general' care staffs, for example with respect to speech or other communication difficulties, or for people with both learning disabilities and mental health problems. But the real test of whether the proposed assessment scheme will operate in the interests of consumers rests heavily on the effective integration of all assessment elements.

Another, potentially disadvantageous, feature of the Paper's proposals rests on the fact that a consumer moving to another local authority area might find that the authority has decided that their needs have changed, or that their assessment needs to be reviewed: consequently their old assessment is no longer held to be valid – which could undermine the whole idea of a nationally portable assessment. We hope that this would not be a common occurrence, but nevertheless urge Government to place a new duty on the Care Quality Commission (CQC) to monitor this closely, and to take robust action, perhaps with the Local Government Ombudsmen, against any local authority which employs such a tactic without proper justification. Ideally, the CQC and the Ombudsman services, including the Parliamentary and Health Service Ombudsman, would set up a single complaints/appeals point and process for service users and carers and, where appropriate, for their advocates.

Entitlement to services

The critical missing element in the Green Paper concerns the lack of enforceable entitlement rights to care services based on people's needs assessments. The research literature on unmet care needs is substantial, and intersects frequently with debate about the eligibility criteria employed by care and support services, and charges for care services. What matters to consumers is not just their right to a properly conducted needs assessment and accurate statement of care and support needs but the crucial matter of the services they actually receive.

Consumer Focus recognises that the Government has attempted previously to promote more fairness and equality in terms of people's eligibility for services, and to highlight the importance of delivering the right services at the right time, for example through its *Fair Access to Care Services* guidance; a revised version of which is currently out for consultation. But people are still being let down, a point readily accepted by Government.

The Paper talks about the introduction of a national entitlement, but an entitlement to what? For example, locally-determined eligibility criteria are likely to continue, which means that variations in levels of entitlement are likely to persist. Most local authorities categorise potential clients according to whether their level and/or complexity of needs is deemed to be critical, substantial, moderate, or low, and usually cater only for the first two 'groups. For a truly fair national entitlement to operate, all local authorities should apply common understandings and criteria (ie a person should not be able to be downgraded from 'substantial' to 'moderate' when they move to another local authority). This would be an important guarantee to include in any future White Paper. It reflects our concerns, stated earlier in this response, that important as local flexibility is it must not in any way undermine the notion and reality of a national care and support service for consumers.

Shaping services around people's needs and views

It is vital that actual service provision and consumers' entitlements are shaped around people's needs so that they receive the care and support they require for their physical and mental health, their independence, dignity, empowerment and quality of life.

Consumers, quite rightly, would expect to receive a reasonably-equivalent amount of care and support regardless of where they live or where they move to; this is one 'postcode lottery' that is clearly of fundamental importance to people's lives and well-being. In some circumstances it is not unreasonable to measure this broadly through inputs – for example a person may only need and want help to get up in the morning and go to bed at night. But even here using crude service inputs as a measure may fall well short of what the consumer really wants, for example she or he may be adversely affected if the service design and delivery means that they 'have to' go to bed at 6.30pm instead of their previously-normal or preferred 10pm.

Consumer Focus understands that, for many management and operational reasons, services can tend to rely heavily on input models but, as Government recognises, what matters to consumers are outcomes, and more generally the experience of using care and support services. We therefore welcome the outline proposal in the Green Paper for an organisation to 'establish the evidence base for care and support', but only if it features strong, integral, consumer input and comprehensive and ongoing consumer participation.

For example the Green Paper bases part of the case for reform on consumers' changing expectations, by which it is assumed that adults and (usually younger) older people with disabilities or other conditions have higher expectations than their forebears.

Furthermore, there is an implication that these changes will tend to increase care and support service costs. It is in everyone's interest that these assumptions are tested properly. Consequently it is imperative that any new organisation should regard it as a priority to establish and develop a very substantial evidence base founded on consumers' experiences, their wants, needs and practical suggestions.

We also regard it as essential for the CQC or another appropriate body to be charged with regularly eliciting comprehensive consumer feedback on the nature and adequacy of needs assessment processes and outcomes. It is many years since the 'medical model' of disability was recognised as deeply flawed and inappropriate, but for financially hard-pressed local authorities and others, such as the DWP, the temptation to fall back onto rigid definitions of capabilities, such as a person's ability to walk a certain distance unaided on a particular day, may be seen to be irresistible. But in reality, some conditions fluctuate, for example arthritis 'flare up', and some people are far more resilient than others in finding effective ways of coping with a particular type of disability in the short or long term. Consumer feedback about their experiences and needs must obviously feed through, and be seen to feed through, to policy makers and others involved in service planning and delivery.

Early intervention

At the same time Government needs to address more robustly the current problem that many people with assessed needs only become eligible for services after they have struggled to cope without services, perhaps for many years. The perverse system which only provides needed services after someone's condition or circumstances have worsened must be reformed. For example, as Mark Lever, chief executive of the National Autistic Society argues: *'For too long people with autism have been misunderstood and discriminated against by a counter-productive system that often lets people reach crisis point before they get the help that they need.'*⁷

Consumer Focus notes that the Government has frequently highlighted the importance of preventative approaches in health and social care, for instance in the DH's *Our health, our care, our say* White Paper, in its *Prevention Package for Older People*, the *Healthy Child Programme*, and so on.

So it will be essential in any future White Paper to be much clearer about putting the Government's emphasis on preventative services into practice, in large part by making sure that those categorised in the 'low' and 'moderate' groups in particular are entitled to receive such services at the right time and in the right ways. In addition, the time is overdue to re-visit the potential preventative role that 'unfashionable' services might offer, such as help with people's gardens, with household cleaning, the use of befriending schemes or help with writing letters to utility companies.

⁷ <http://www.guardian.co.uk/society/2009/jul/14/social-care-green-paper-reaction>

6. Personal budgets

Consumer Focus welcomes the potential opportunities for consumers offered through the proposed increase in the use of personal budgets.

However, there is a basic confusion in the Paper about who will be eligible for a personal budget. For example whether all those with a needs assessment will be offered a personal budget, or only those deemed to be eligible for care services (see, for instance, page 60 of the Green Paper). It is not clear whether this confusion arises from poor standards of drafting, or whether it signals an intention to offer new options to consumers who are not currently deemed to be eligible to receive services, such as those in 'Low' or 'Moderate' needs categories. Obviously this fundamental point must be clarified in any subsequent White Paper.

The reality of consumer choice

Whatever decision is made about which consumers are eligible in principle for the receipt of personal budgets, there is an equally important clarification required about the extent to which a consumer's use of a personal budget has to or should reflect their needs assessment as defined by relevant practitioners and/or professionals.

For example, if a care and support consumer decided to use a significant proportion of their budget on taxi fares to and from local pubs and for drinks with friends and acquaintances, could or should a care manager or other care and support professional/practitioner have the right to intervene and try to persuade the consumer to reduce such expenditure in order to help pay for a healthier diet, a physiotherapy service, or perhaps fees for 'constructive' daytime activities? What could or should happen if the consumer rejects such a suggestion – even if as a consequence it might put their physical (and/or mental) health at risk?

Similarly, what could or should happen (if anything) if a disabled consumer decided to spend part of their budget on a non-respite holiday, rather than on aids and adaptations for their home, for example? The consumer could argue, with justification, that human rights legislation affords them just as much protection in terms of their private life as someone not in receipt of a personal budget; they could also argue that such expenditure was justifiable in terms of their quality of life.

Many more illustrations could be employed here but the main point is the need to 'ground' discussions about how personal budgets allow or enable consumers to exercise real choice. This has to include any overt or covert constraints and justifications for these employed by local authorities – which increasingly need to be spelt out at an individual and general policy level (and made publicly available to the extent that is reasonable and lawful under data protection and equality and human rights legislation).

Obviously, the Government also needs to be clear about the extent to which the care and support 'system' should or could employ a risk assessment framework in relation to consumers who need some publicly-funded care and support and under what circumstances. As mentioned previously there could well be a 'trade-off' between individual service users' preferences with respect to their spending of their personal budget and what health or social care professionals would deem to be sensible in terms of a person's health and well-being. There could also be important matters relating to the ability or capacity of a service user to make informed choices about their spending 'versus' the actual or potential risks to which they might be exposing themselves.

This is not a 'new' subject in the social care field in particular (where judgements about what is or is not an acceptable risk is part of professionals' practice), but a large scale roll-out of personal budgets might justify the introduction of a more transparent and generally-available set of guidance; to protect both individuals' ability to make choices and to ensure their safety. Consumer Focus accepts that this is a complex and difficult area, but urges the Government to explore it more explicitly in any future White Paper.

The very basis of personal budgets and direct payments policies rest on the notion of consumer empowerment and choice, in so doing they attempt to 'mainstream' people who might in the short or long term require the use of care and support services. Therefore the balance between general consumer rights and the various duties of care placed on some professionals and practitioners needs to be made explicit in any future White Paper.

For instance, should a consumer be able to use part of their budget to employ a personal care assistant who may not in the opinion of experienced social care staff have sufficient knowledge or skills (eg in manual handling) to offer safe care, even though the consumer has an extremely good and constructive relationship with the assistant? Could or should the local authority suggest or offer training for the assistant, if so is the consumer expected to pay, or not? Again, to what extent should consumers' rights to 'take risks' in employing individuals (which includes consumers not actually being employers in the legal sense) be upheld in all circumstances?

Consumer Focus understands completely the need for the new Vetting and Barring scheme for those deemed to present a risk to vulnerable adults, but notes that, in England, the Safeguarding Vulnerable Groups Act 2006 specifically excludes personal assistants. Care and support service consumers can already request Criminal Records Bureau (CRB) checks for individuals, and the 'personalisation tsar', Jeff Jerome, the national director for transformation of social care, was reported last year as saying that there was no evidence to suggest that people employed directly by service users were likely to pose greater risks than registered care staff⁸.

Consequently it is perfectly possible in theory for consumers to employ assistants who may have a criminal record of some kind and/or who may have been suspected (or charged or convicted) of abusing adults for whom they provide services. Therefore it will be important in any future White Paper to explore the balance between consumers' rights (including safety) and behaviours and activities which could put them at serious risk. It should also make proposals which can both protect people's rights and provide effective interventions if something is going wrong.

Making informed choices

A key task for the suggested independent body would be to ensure that every local authority in England, including agencies under contract to them or clearly involved in care and support services in their locality, provide clear information about what is on offer, under what eligibility rules and charging arrangements (and prices). This is so that consumers can make informed decisions about whether a personal budget would suit them, and whether they would, for example, wish to arrange all of their care independently, or use one or more statutory or contracted-out services. Obviously, such information would have to be offered in a variety of formats and languages, and include details about local advice and advocacy services.

⁸ <http://www.communitycare.co.uk/Articles/2008/10/22/109753/social-workers-want-personal-assistants-to-be-regulated.html>

A central assumption of the personalisation agenda, including personal budgets, is that it will help to promote and secure consumer choice. This requires Government to turn a spotlight on local care and support markets or quasi-markets. For example it may be simply unrealistic to expect that more than one specialist service provider, for example for people with learning disabilities who have mental health problems, will always be available within a particular local authority area. In this case consumer choice may only be secured by other neighbouring local authorities offering their specialist service(s) to the consumer, though this could present budgetary difficulties unless local authorities have pooled budgets or reciprocal arrangements in place. Any future White Paper will have to address this issue, including the need to be open with people locally about what is or is not available, and why. This should be driven by far more democratic and participatory mechanisms than exist at present.

There may also be limits to choices which are dictated by consumers and their families, for example some may feel strongly that it is only feasible to use a residential palliative care service which operates in their area; at such a difficult time close family members may not be able to countenance long travel times or significant travelling costs. Again, a White Paper should acknowledge that such constraints may be unavoidable.

Issues around real choice also include care charges. For example last year a survey by the Coalition on Charging found that 80 per cent of people who no longer used services cited costs as one of the reasons, and 29 per cent felt that their extra costs of disability had not been reflected in the test of resources determining how much they paid⁹.

This issue overlaps with the general funding issues which feature so largely in the Green Paper (see below). But it could be argued that, unless more resources nationally and locally are directed towards care and support services, all that might happen is that those with inadequate personal budgets will seek to stretch their money by cutting back on services or using cheaper services (if they exist locally). One obvious consequence would be a reduction in consumers' ability to exercise real choice; another might be a reduction in people's health and well-being.

Consumer Focus believes that, at the very least, any future White Paper would have to propose that the new independent body is tasked with investigating and monitoring the extent to which personal budgets enable consumers to improve their ability to exercise real choice (to meet their needs and preferences). Furthermore, it will be imperative that consumers' views and experiences form the cornerstone of such a programme of activity.

Potential implications for services

On a broader note, a large-scale rollout of personal budgets carries with it the danger that skilled experienced practitioners (such as social workers) will be displaced by a wide range of (perhaps unqualified or unskilled) assistants and others. Understandably, the British Association of Social Workers fears that this could lead to cuts in local authorities' adult care services funding and workforce levels and capabilities. Any future White Paper must address this matter because any policies which might effectively drive down service quality would present a serious risk for consumers of care and support services.

Most consumers are likely to expect that care and support services are of a good quality, or at the least of an adequate quality, and many expect or need there to be sufficient capacity to respond in a timely way to their requests for assessments or service provision. Consequently if the rollout of personal budgets leads to a diminution in 'mainstream' services provided by or through local authorities the consequences for consumers could be seriously damaging. It is also possible to foresee some local

⁹http://www.ncil.org.uk/uploads/pdf/10921658_Coalition%20on%20charging%20NCIL%20rel ease.doc

authorities taking advantage of this situation to rationalise and restructure some services out of existence for reasons based on cost-cutting, rather than consumer needs.

In addition, any such shrinkage might, paradoxically, lead to an increase in the costs of providing services, with a consequent increase in charges for the consumer. A team working with a minimum complement is more likely to have to engage (relatively expensive) agency staff on a short term basis if demand increases, for instance during a period of cold or very hot weather. Also, local authorities have been urged by Government for many years to seek value-for-money solutions by striking volume-based contracts with local suppliers (eg for care home placements for adults or older people, and for domiciliary care); such medium term contracts have given independent sector providers a degree of financial security and stability which has helped them to reduce 'unit costs' and therefore charges to local authorities and so to consumers.

We are, of course, firmly committed to the person-centred care agenda, and to consumers having the option of using personal budgets in ways which suit their needs and wants. But we are equally exercised by the need for consumers to have universal access to affordable good quality services, especially people in vulnerable or difficult circumstances. It is imperative that any future White Paper sets out a substantive and evidence-based consideration of the subject of personal budgets, including a proposal that any new independent body would be tasked with gathering information, monitoring and reporting on these matters. One of its central tasks must include the evaluation of the quality and accessibility of information for consumers, especially the effectiveness or otherwise of 'signposting' and the ease with which it is possible to access appropriate advocacy services.

7. Funding

A principled approach

At some point in most consumers' lives, care and support services may be needed and sought, though not always delivered; this includes people who are able to self-fund all necessary services, and those who cannot, in the short and/or long term.

Previously in our response we have cautioned against crude categorisation of people according to disability, age, etc. and do so again in relation to the suggested choices around funding of care and support services. There is for example a danger of assuming that funding issues should be predicated primarily on the needs of the growing number of older people; this is neither appropriate nor justifiable.

Consumer Focus notes that the Green Paper rejects increased funding from general taxation basically on the grounds that it would be unfair to place extra tax 'burdens' on those of working age in order to help meet the needs of their parents or grandparents, in effect.

It is worth pointing out that such arguments are not generally employed in relation to the use of general taxation to fund children's' education, and NHS services, for example. It is important that the funding debate is not framed in unhelpful and divisive ways which could, for example, help to stoke intergenerational conflict. Nor should it employ any terms and assumptions which could be used to feed uninformed opinions about who is 'deserving' (of State help) and who is not. For instance, people with substantial and long term caring responsibilities for a disabled or ill child or adult relative are less likely than many others to have had opportunities to amass significant savings.

Consumer Focus broadly agrees with the principles proposed in the Paper for reform of funding, namely that it should be fair, understandable, effective and enduring. However we would add the proposals also need to be based on principles such as affordable access to services, transparency, consumer support and empowerment, monitoring and evaluation, and the need for easy and effective complaints and redress processes. Any future White Paper would also have to ensure that proposals do not fall foul of equality and anti-discrimination laws and duties.

While we accept that many care and support services will require there to be more financial resources available to them, indeed some are already in great need of additional funding, we would have expected the Green Paper to have provided a more considered examination of projected shortfalls and their consequences, including those which can lead to unintended extra care costs, for example for the consumer or the NHS. Any future White Paper must be much more explicit about the reasons for and actual projected amounts.

Also, as mentioned previously, the Green Paper's heavy emphasis on the increasing number of older people and the assumption of a roughly proportionate increase in the costs of their care (especially in relation to care homes) leads to a rather unbalanced picture. There is, for example, a growing number of adults of working age who need to use care and support services, and the quality and effectiveness of these services will help to determine the extent of their care needs in later life. Also, for instance, the number of disabled children is projected to rise from 700,000 to 1.25 million by 2029, with a consequent increase in the number of disabled young people moving into the adult care sector, and more parents or carers needing help from services¹⁰. Any future White Paper must be properly comprehensive and accurate in this respect.

One of the central issues in the Paper concerns notions of fairness, often with reference to the inputs made by those who were involved in previous Government 'engagement' events. Perhaps unsurprisingly therefore, fairness is often framed in terms of people's levels of savings and associated assumptions about their financial behaviour – basically that 'spendthrifts' should not be treated in the same way as those who have built up savings.

Consumer Focus urges great caution about this matter. A consumer with mental health problems for example may have found it difficult to obtain and keep a reasonable paid employment record, and could also find it impossible to obtain (or afford) any insurance policy to help cover care and support costs. Many consumers with substantial caring responsibilities would, with justification, reject any suggestion that their poor financial circumstances were in some way 'their fault', and could make the counter argument that unpaid carers save the state £87bn a year, or about £14,500 each on average, according to a survey last year for Carers UK¹¹.

Any sound notions of what constitutes fairness would also have to take into account the unavoidable extra costs of disability, for example; costs which may well render it difficult or impossible for some households to build up savings or be able to pay a significant amount into private insurance policies. It must also recognise for instance that some older people with disabilities or limiting long term conditions may well have paid income tax and national insurance for a great many years (as well as taxes such as VAT), and would regard it as grossly unfair to be required to pay yet more for needed care and support services in later life.

¹⁰ <http://www.epolitix.com/latestnews/article-detail/newsarticle/budget-must-support-disabled-children/>

¹¹ See for example <http://www.guardian.co.uk/society/2008/jun/09/carers>

In short, discourses around ‘fairness’ in relation to consumers’ payments for or towards care and support services need to be based on a broad and nuanced understanding of consumers’ circumstances, needs, and expectations.

Clear information and processes

Before moving on to an outline consideration of the Green Paper’s different suggestions for funding, Consumer Focus maintains that much more attention needs to be paid to matters of transparency and information in any future White Paper. Consumers do want, nor do they deserve, to be faced with baffling and multiple forms and processes concerned with money and entitlements, means tests or taxation matters; especially at times of stress.

Bearing in mind the already-significant under claiming of benefits, especially but not only by older people, it will be important in a future Paper to balance intellectual justification for any particular set of funding proposals with the demands of a system which can be easily understood by the vast majority of consumers (and which will help enable them to judge whether to make a complaint if necessary, among other things).

Funding options

There are three funding proposals generally favoured in the Green Paper. One is a partnership model, with costs being shared by individual consumers and the state; the amount being determined through a means test, and the state contribution could utilise Attendance Allowance, and possibly the Care Component of Disability Living Allowance. Another is an insurance-based option, either state-run or a public/private sector mixture, with contributions being paid by instalments or a lump sum before or after death. The third, a so-called comprehensive scheme, would involve everyone over retirement age being required to pay into a state insurance scheme, the amount being subject to a means test.

Consumer Focus supports the King’s Fund argument that it is essential for the Government to set out in any future White Paper the potential costs, to the consumer and to taxpayers in general, of the different options¹².

Consumers will need to have reasonably well-costed information to help enable them to judge the consequences for them and their families. It will of course be crucial for the Government to involve consumers in any and all further considerations of the funding of care and support services.

As outlined previously in this response the various proposals must also be tested for fairness and equity; again much more information needs to be made available to consumers before such testing can occur. For example it is currently unclear whether any or all of the options would easily or automatically enable a consumer who experiences a sudden and unexpected drop in income and/or other financial resources, such as assets, to be treated fairly, or those facing the onset of a disabling condition.

Consumer Focus is also concerned about the proposal to ‘integrate’ some elements of disability benefits into the general funding of care and support services. The ones named are Attendance Allowance and Disability Living Allowance, presumably only the Care Component.

¹² see www.kingsfund.org.uk/research/topics/social_care/shaping_the_future_1.html

As we and others have argued, flawed as these benefits might be, they do in part recognise the additional costs of disability borne by individual consumers and their families. Secondly, we are concerned that if these universally-available benefits are collapsed into local authorities' budgets consumers become ever more reliant on the decisions made by local care managers and others, leading potentially to more inequalities and 'postcode lotteries'. Thirdly, this proposal could for many consumers deprive them of the right to use 'their money' as they see fit. The advent of personal budgets would not necessarily deal with this problem as local care budgets could, for example, be cut back if a local authority is particularly hard-pressed financially.

Some of these problems could be avoided in principle by Government adopting a fully national system, where the same level of need would attract the same level of funding wherever people lived in England. But, as the Paper recognises, there are large variations across the country in the costs of some services (especially those provided by the private sector), which would create unfairness in the amount of service available to different consumers with the same level of need. Consumer Focus shares this view, and suggests therefore that a part-national part-local scheme would offer better and fairer outcomes for consumers: a certain degree of local flexibility within nationally-determined upper and lower limits would appear to be logical and appropriate.

Finally, we urge the Government to be more innovative in its approach, and put before consumers a wider range of, properly costed, suggestions. For example it needs to offer ways of creating a less abrupt and distressing transition for those who have fully funded their care but whose resources are becoming depleted. This would have the added advantage of not maintaining a sharp divide between those who 'opt out' of public care services and those who do not or cannot. Another example of a long-running problem which needs to be addressed properly is the inadequacy of equity release schemes for those with significant housing assets but inadequate income.

8. Key issues and recommendations

Consumer Focus is strongly committed to the need for the best possible care and support services to be available. Poor services tend to produce not only poor results for the consumer but also an increase in the likelihood that the consumer will as a consequence require more intensive (more expensive) services sooner than necessary and perhaps for longer than necessary.

The Government must be clear about the intended scope of the national care service. This should include clear proposals on any further developments envisaged for further 'joining up' of service planning and delivery.

Any subsequent White Paper or policy proposals should be based upon a comprehensive and joined-up approach to care and support services, including healthcare, housing and community equipment services.

The Government should clarify what services are included within any new National Care Service, including what services people are entitled to. The over-riding considerations should be based on people's requirements for help and support, and focus on the need for safety, dignity and quality of life. Consumers should be clear about what constitutes a healthcare service or social care service, and whether and in what circumstances the consumer is expected to pay, in part or in full (consistency and predictability are particularly important when people are facing difficult circumstances).

Consumer Focus welcomes the proposal for consumers to have the right to have their needs assessed in the same way regardless of where they live. But the Government must also guarantee that there will be a common understanding between all local authorities of people's needs assessments and implement such a common framework rigorously and robustly.

A robust evidence base is required as a basis for any major changes in funding arrangements for care and support. The Government needs to be much clearer about the size of projected shortfalls, the basis on which such calculations have been made and whether service reconfigurations or more innovative approaches to service design and delivery might deliver more for less.

Any subsequent White Paper and policy proposals should be based upon a more nuanced and clearer understanding of the range of people's circumstances that affect their need for care and support services. This should include a proper recognition of the extra costs of disability and of costs associated with major caring responsibilities, such as having to use taxis rather than public transport or needing extra heating.

Consumers should have easy access to clear information about the services to which they might be entitled within a national care service and any eligibility criteria. The service should also provide a competent, easy to access and free advice and advocacy function for consumers.

A national care system will need to incorporate effective, fair and robust complaint handling systems and provide consumers with easy access to fair and independent redress.

The Government needs to clarify the intended remit, powers and duties of any new overview body that is proposed for care and support services. Any new organisation must include a substantial amount of consumer involvement if it is to command consumer trust and support, and in order for it to establish a robust evidence base it must regularly seek to engage with consumers' needs, views and experiences.

We look forward to seeing the Government's more detailed proposals on these issues in particular, and to contributing to the ongoing debate about a new care and support system in England that is fairer, simpler and more affordable for everyone.

Shaping the future of care together

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