

Shaping the Future of Care Together

Equality Impact Assessment

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Introduction

Care and Support Green Paper

Our society is going through dramatic change. With demographic changes and increasing, it has been estimated that by 2026 there will be 1.7 million more adults who will need care and support. Our existing care and support system is a legacy, not of a single bold reform like the creation of the NHS, but of a series of more limited and incremental steps. People have told us they have a number of concerns with regards to the current system. In particular, the current system is seen to:

- be unfair as it is not clear what state support people maybe entitled to and often many people have to deal with the potentially high cost of care themselves, with little support offered by the state.
- be confusing as there is very little offered by way of advice and support,
- have wide variations in the standards and quantity of care and support offered by different local authorities
- not effectively meet all the needs of those who require care and support.

Changes in our society mean that with growing numbers of people who will require care and support in the future and growing expectations of what public services should provide, radical reform of the system is needed, to respond to these pressures as well as to address the concerns that people have told us they have about the current system.

In 2007, the Government announced its intention to publish a Green Paper in 2009 to consider potential ways in which the current system could be reformed to meet these challenges. As part of considering and evaluating which reforms are suitable and will achieve better outcomes for all, the Government recognises that it is essential to assess the likely impact of the reforms on people who use the system. People who use the current system are diverse, from different ethnic backgrounds and age groups and with different levels of disability and need. This is why the Government has conducted an Equality Impact Assessment (EIA) to understand and assess the potential impact of the proposals on key equality strands, and where possible seek to redress any inequality within the current system and promote equality for all within any future care and support system.

What does the EIA cover?

This EIA has drawn on currently available evidence to look at the likely equality impact of possible reforms to the care and support system on people according to their age, disability, gender, ethnicity and race, religion and belief, and sexuality. In addition to these groups, we have also considered the Green Paper proposals' impact on rural communities and human rights. It looks at the following:

- What is care and support?
- The current system's impact on equality strands

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- The case for change engagement process.
- Impact of the specific proposals outlined in the Green Paper on different equality strands.
- A summary of the main messages on the impact of reforms on the different equality strands.
- Recommended actions.
- Methodology.
- A full list of the evidence reviewed.

It should be noted that conclusions drawn within the EIA are based on current evidence. Evidence available in this area is primarily focused on the current care and support system and the inequalities within it. Therefore, it is difficult to say with any certainty what the impact of the proposals outlined within the Green Paper may be on the various equality groups. However, the aim of the Green Paper is to improve equality and diversity within the system.

In addition, the Green Paper presents a number of options for public consultation. Depending on the outcome of the consultation process, further policy consideration and evaluation will need to be conducted on the specific proposals which may be introduced. At that stage further work will be required to review and update the EIA to assess more definitively how any future reforms will impact on the equality strands, identifying potential issues of any policy adopted and looking at ways in which any negative effects can be avoided or mitigated.

1. What is care and support?

“Care and support describes the activities, services and relationships that help people to be independent, active and healthy – as well as be able to participate in and contribute to society – throughout their lives.”¹

The term refers to a mixture of financial, practical and emotional support, and the support provided by families, all of which help thousands of people every day.

People might need care and support to:

- get in and out of bed
- carry out basic household chores
- prepare their meals
- pay their rent and organise paying bills
- make sure their homes and their workspaces are adapted to suit their needs
- recover after an operation or illness
- come to terms with the death of a loved one, or
- look after children and fulfil their parenting responsibilities.

Over the last ten years, many important changes have taken place in how care and support is provided, and a major reform programme – Putting People First² – is already under way. The reform programme seeks to improve the quality of services for all and ensure that the system is tailored to the individual needs of the people who use it. However, there are still a number of underlying problems within the current care and support system, particularly for the various equality strands which need to be addressed.

¹ From Department of Health (2008) *The case for change – why England needs a new care and support system*

² Department of Health (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*

2. The current system's impact on equality groups

Demographic change

As the number of people with needing care and support increases, local authorities are tightening the eligibility criteria for social care in order to cope with the demand for support. This puts increased pressure on carers and on individuals to pay for their own care and can lead to people being left without the care and support they need.

Carers

It is commonly acknowledged that women, older people and people from some BME ethnic groups (such as Pakistani and Bangladeshi communities) are more likely to be carers. This often results in informal carers reducing their employment hours or foregoing employment altogether in order to provide the necessary level of support. The Equality and Human Rights Commission (EHRC)³ reports that a survey revealed that a third of carers have never been in paid employment and 20 per cent have declined work opportunities because they are responsible for providing care and support. The study notes that this 'discrimination by association' inevitably affects their ability to save for their own future care needs and for their children. In addition, studies have highlighted the negative impact on carers not just financially, but also in terms of their general health and well-being, and suggest that the majority of informal carers find themselves stressed and overwhelmed by their caring responsibilities.

Individuals paying for their own care

Much of the evidence on the impact of the current amount that individuals in need have to pay privately is within the context of higher levels of poverty among older people. In terms of other specific equality strands' vulnerability to poverty, older women, black and minority ethnic (BME) older people and older pensioners are found to be particularly vulnerable.⁴

Available evidence suggests that gender is a key variable, with older women being less financially well off and more in need of residential care than older men. Only about 13 per cent of women of pension age are entitled to full basic State Pension in their own right.⁵ In terms of increased need for residential care, nearly five times as many women as men are in institutional care, but they are less able to afford it.⁶ Similarly, of the 3.5 million households in Britain that cannot afford care for more than one year from income and savings, 1.6 million are single women and 0.6 million are single men. This is likely to mean that older women are more adversely affected by the costs of privately

³ EHRC (2009)

⁴ Naegele and Walker (2002) cited in Raynes, Clark and Beecham (2006)

⁵ Raynes, Clark and Beecham (2006)

⁶ Mayhew (2009)

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purchased residential care, as a result of both their increased need for this form of social care and their lower income and savings.

In addition to older women, there is evidence to suggest that older people living in deprived areas in England are at least twice as likely to be living in poverty as those in Britain as a whole, and that this is particularly acute among older Black Caribbean, Bangladeshi and Somali people.⁷ The impact of poverty on these groups of older people reduces their ability to afford individual contributions to social care as they are less likely to have access to equity that can be released. This is exacerbated by the under-claiming of means-tested benefits among these groups.⁸

Another group considered in the evidence in relation to ability to pay privately are low earners of working age. Recent research suggests that 70 per cent of low-moderate earners are likely to be ineligible for any state funding for care and support, yet they have incomes that only just fall above the eligibility criteria, meaning that privately purchased care can be unaffordable.⁹

However, the problems within the current system are not just limited to demographic changes and financial pressures. There are a number of problems within the way the current system operates, some of which are common to all users and some of which have specific impacts on certain equality groups. These problems are considered below.

Lack of transparency within the system

The care and support system is confusing and opaque and, as a result, many people find it difficult to know what makes up care and support and what financial support they are eligible for and how to access it. The Commission for Social Care Inspection (CSCI) (now Care Quality Commission) found that people who qualify for state support are more likely to receive better information (or be guided to information) than those who don't, who are left to find their own way through the system. Signposting from local authorities is considered to be weak, and this often results in people being steered into care homes without any real consideration of alternative options for care. For example, fieldwork conducted by CSCI¹⁰ demonstrated that a number of self-funding people in care homes have not experienced a needs assessment or considered any alternative options.

The current complex means-testing system has been widely recognised as being unfair to 'savers', particularly those people on low incomes who have accumulated fairly modest savings for old age.¹¹ It is likely that the current system, as it stands, can act as a disincentive to save for some people. Such people are often liable to pay a significant portion of care home fees and domiciliary care fees. The Wanless review¹² argues that

⁷ Scharf et al. (2003) cited in Raynes, Clark and Beecham (2006)

⁸ Raynes, Clark and Beecham (2006)

⁹ Resolution Foundation research cited in EHRC (2009)

¹⁰ Henwood and Hudson (2008)

¹¹ Wanless and Forder (2006)

¹² Wanless and Forder (2006)

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a large number of older people have very little understanding of the state support that is available to them. In particular, older people often reach retirement age with no knowledge of the fact that state-supported care is subject not only to needs testing but to means testing as well. The review also notes that the complexity of the means-testing system often discourages older people from applying for state funding. This suggests that needs may often go unidentified until a point where they are escalated to a level that requires more expenditure at the individual and state level. It also means that mistakes are easily made. The review highlighted that approximately 6 per cent of people currently in care homes whose financial profile indicated that they could have been entitled to some state support were unaware that they were eligible (due to lack of understanding and knowledge of the system) and were self-funding all their care.¹³

Lack of consistency within the assessment process and portability of assessment

There is widespread discussion in the literature that a lack of national consistency in needs assessment criteria often means that there is considerable variability across local authorities on those who are assessed as eligible or ineligible for social care. The Wanless review¹⁴ has referred to this variability as a 'postcode lottery' that can often result in significant inequalities in access. The EHRC¹⁵ notes that one in which way this manifests itself is by restricting the movement of people requiring care and support, as there is no guarantee that moving from one local authority area to another will result in the same level of care despite people's needs remaining the same. This means that older people can find themselves in a predicament where they are unable to move nearer to relatives or other sources of informal care as they may face a reduction in the level of support they are eligible for. For working-age disabled people, the disparity in levels of support they would receive in different areas can restrict their ability to move in order to take up employment opportunities elsewhere.

Another inconsistency that often arises is the manner in which the needs assessment is conducted by staff in local authorities. In their review of the eligibility criteria, CSCI found that staff are prone to 'bending the rules' which can run the risk that 'who shouts loudest is listened to' while others are overlooked.¹⁶ The study notes that this can impact negatively on ethnic minority groups who are less comfortable about identifying themselves as needy and can thus end up not receiving the support they are entitled to. Another study by CSCI¹⁷ notes that there is also the propensity to neglect issues of cultural importance within the assessment process and in fact make faulty assumptions about people from ethnic minority groups.

Another CSCI study¹⁸ notes that assessments are often carried out over the phone and older people often downplay their needs, thus not receiving the support they need and

¹³ Wanless and Forder (2006) p. 103)

¹⁴ Wanless and Forder (2006)

¹⁵ EHRC (2009)

¹⁶ EHRC (2009)

¹⁷ CSCI (2008a)

¹⁸ CSCI (2008a)

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are entitled to. The likely impact of these inadequate assessments means that those needs that may contribute significantly to the well-being of these individuals are ignored.

There is also some evidence suggesting that people from lesbian, gay, bisexual and transgender (LGBT) groups find themselves in an assessment process that fails to correctly assess their needs. In a survey conducted by CSCI,¹⁹ only 24 per cent of people felt that their needs as an LGBT person were adequately considered at their last assessment. The same research found that only 14 per cent of care homes gave sexual orientation in a list of factors that they would take into account during assessment or care planning. Additionally, less than 1 per cent said that they had done any specific work around sexual orientation and assessment or care planning.²⁰ This is likely to result in the provision of services and support that inadequately meet the needs of these individuals.

Another group that has been identified as being negatively affected by the current eligibility system are those 16–17-year-olds that are in transition between children's and adults' services.²¹ The study notes that the risk for these young people is that they may fall out of the system for good.

A number of patient groups have been identified as particularly disadvantaged by the current needs assessment process. For example, people with mental health problems currently enter the health system directly without a social care assessment or any access to support, and people with learning disabilities who are judged ineligible for learning disability support are not likely to receive any further assessments or have any contact with social care.²² This suggests that there may be a wide range of needs that go unidentified for these individuals.

There is some evidence about potential carer issues to consider when assessing the needs of people from LGBT groups. Informal carers are often friends or partners of the individuals in need, especially in cases where the family disapproves of their sexual orientation. Providing these individuals with the opportunity to nominate their 'next of kin' is considered vital in ensuring that they get the care they need.²³ This has been echoed in fieldwork conducted by COI²⁴ which found that some LGBT respondents were keen that a wider definition of terms such as 'family' or 'carer' be used in assessments.

Effective use of state money

Older people are more likely to have low-level needs that they define as 'that little bit of help'. Such help often contributes greatly to their quality of life. Low-level need has been defined in a number of studies²⁵ as help with housework, gardening and other practicalities. It is primarily older people that value these needs as meeting them

¹⁹ CSCI (2008c)

²⁰ CSCI (2008c)

²¹ CSCI (2008a)

²² CSCI (2008a)

²³ CSCI (2008c)

²⁴ COI (2008)

²⁵ Henwood and Hudson (2008); Raynes, Clarke and Beecham (2006)

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contributes greatly to their quality of life. Being able to manage the house is important to older people, not only because they spend a large amount of time there, but also because it is important for them to keep a sense of identity and control over their lives. However, it is becoming increasingly difficult for these older people to access help at home due to limited availability. A CSCI study²⁶ notes that the risk for these people is that they will try to perform these tasks themselves which could lead to falls or other problems. The absence of a preventative agenda has also been identified as a key problem within the current system for these groups, who could benefit from some type of preventative intervention, to help reduce the risk of their level of need escalating further to the point where they then become eligible for care and potentially have higher costs that need to be covered.

There is some evidence²⁷ that for people from LGBT groups an important 'low-level' need is getting involved with other people from their community. Such ongoing involvement can be very important for their identity and self-esteem. However, the study argues that it is often difficult for these people to make such social arrangements on their own.

Choice and control

Personal budgets are a fairly recent development and are intended to enable the personalisation of care services by allocating a budget to people who can then decide how to spend it to meet their assessed eligible care needs and agreed outcomes, in line with a personalised support plan. The allocated budget²⁸ can be used to design and purchase support from the public, private and third sectors. There is currently variation across different local authorities in terms of how personal budgets for people eligible for adult social care are being implemented as well as the timing of that implementation.

Groups potentially able to benefit from personal budgets include older people, people with mental health problems, people with learning disabilities, people with physical and sensory impairments, and carers. People can choose the way in which the personal budget is deployed: they can take cash in the form of a direct payment, a notional personal budget managed on their behalf where they influence the choice of services, or a mixture of the two.

Evidence on the current impact of personal budgets across the equality strands is largely positive in terms of impact on well-being, increased choice and control, cost implications and unmet need. However, there are still some unresolved issues concerning the way in which personal budgets are provided.

For BME and LGBT groups, personal budgets have been shown to have the potential to offer greater independence and flexibility in support arrangements. For BME groups, this can mean improved access to culturally sensitive, tailored support. However, such positive impacts on well-being can also be hindered by a lack of options in the market to provide culturally sensitive care support, limiting the choice available to these budget

²⁶ Henwood and Hudson (2008)

²⁷ CSCI (2008c)

²⁸ Individual Budgets Evaluation Network (IBSEN) Report (2008)

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holders. For LGBT budget holders, personal budgets are seen to have greater potential to deliver personalised care than traditional services, in that it better meets the needs, lifestyle and cultural needs of LGBT people, for example the ability to employ a care worker who is also gay if that is what they wish. Unlike BME budget holders, older LGBT people are more likely to live on their own and do not have ready access to informal care and are therefore more likely to depend upon formal care services. Some LGBT service users may be fearful of having a homophobic care worker. However, as with BME communities, the supply is not developed enough to meet demand for certain types of support and LGBT users report experiencing difficulties recruiting gay care workers.

For older people, the evidence found that personal budgets have less of a positive impact than on other equality groups:

1. Older people were seen to be resistant to the idea of personal budgets, due to what many of them saw as the 'additional burden' of planning and managing their own support. However, individuals have the choice of whether they wish to manage the budget themselves or ask their local authority to do so on their behalf, and therefore greater awareness of the choices people have needs to be achieved.²⁹
2. Older people are also more likely than other groups to under-assess their social care needs when filling out self-assessment forms and so particular skills are required of care managers when setting out the support and options that are available. This is a consequence of older people often having low expectations or wanting to downplay impairments. The impact of under-assessing their needs in the self-assessment could be a reduced personal budget.
3. There was a concern about personal budgets and individual personal safety, particularly for older people. The EHRC report on the future of care and support³⁰ argued that promoting greater independence among older and disabled people requires a consideration of the balance between risk taking and financial and personal safety. On one hand, personal and individual budgets, by giving people greater control over choosing carers and support, can prevent negligence and abuse. On the other hand, older people who are less confident or face communication difficulties may be at greater risk of financial exploitation and abuse. For example, approximately 342,000 people over the age of 66 experienced some form of neglect or abuse during 2006/07. The EHRC report highlights the need for greater information and support to be provided to ensure that older people feel confident in managing or letting others manage their care.
4. Recruitment of care workers in rural areas is problematic and constraints on workforce supply include limited access to transport, low wages and a smaller pool of suitable applicants. Personal budget holders in rural areas, who tend to be older people may therefore have to pay more for their care. Isolation can have an adverse impact on the well-being of older people in rural areas, so the more flexible and innovative alternatives to traditional care services that are now available to people with personal budgets (e.g. arranging for a carer or a friend to take them to bingo) can have positive impacts through reducing this isolation.

²⁹ Individual Budgets Evaluation Network (IBSEN) Report (2008)

³⁰ EHRC (2009)

3. The case for change engagement process 2008

Last year, the Government held a six-month engagement process between May and November to ask people what they want from care and support, and how well their needs are being met at the moment. The process gathered opinions from stakeholders and the public (including those from the various equality strands) on the various key questions about the fundamental principles of a future care and support system. The engagement investigated where people thought the balance of responsibility should rest between families, individuals and the state and whether the system should be the same for everyone or varied according to various circumstances such as:

- the care and support needs of individuals
- local and national priorities
- the financial status of individuals requiring care and support
- the vision for a future care and support system.

As part of the process, a range of consultation exercises with service users, members of the public and user-led organisations were conducted. These included a number of deliberative events, in-depth interviews, workshops, and website, email and letter responses. This research has provided an indicative snapshot of public opinion which has helped to inform this EIA regarding what the future of care and support – including the vision, funding alternatives, means and needs testing, and the role of the Government, society, community, individuals and families in the provision of care – could mean for different equality strands.

The vision for the future of care and support was received well by participants and respondents across consultations, particularly the emphasis on dignity and respect. There was some concern about encouraging older people to live independent lives, as this was regarded as being too great a responsibility for some. Participants in the deliberative events suggested that choice and control were perhaps most important.³¹

While the vision was well received, there was significant concern about how this vision could be translated into practice. Participants felt that a more joined-up approach between local authorities and the third sector was needed.³² They also felt that the Government needed to take responsibility for educating the public by providing them with the information and guidance they need to make appropriate care and support choices.³³ The important role of families and communities in providing care and support was emphasised, and participants were keen to stress the need for financial support and respite for informal carers.³⁴ However, the ‘inclusivity’ consultation conducted by

³¹ COI (2008a)

³² CSCI (2008a); Henwood and Hudson (2008)

³³ CSCI (2008); Henwood and Hudson (2008); Wanless and Forder (2006)

³⁴ Henwood and Hudson (2008); Wanless and Forder (2006)

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Ipsos Mori³⁵ found that informal caring support was valued most by traveller, gypsy, Pakistani and Punjabi communities, with older people with impairments and those living in rural areas having higher expectations of the Government and the care and support they are entitled to. There was some concern that there needed to be a change in attitude towards older people and disabled people so that they are better able to live full lives through social activities, community activities and paid work.³⁶

With regard to funding for care and support, participants recognised that the system needed to change but were not clear about how it needed to change. Some had support for state contributions topped up by individual contributions through an insurance. Others supported increased taxation.³⁷ A number of online respondents³⁸ felt that the problems in the current system needed to be addressed such that individual contributions didn't penalise those who had saved for their old age. In the 'inclusivity' consultation,³⁹ there was a consensus on fairness and equality and on the idea that everyone should contribute rather than having payments made on an individual basis.

Opinion was also mixed on whether those on low incomes should be financially targeted. Some felt that the fairest solution was a model based on NHS principles where care was free at the point of need. Additionally, some felt that means testing was fairest whereas others felt that a national minimum standard of care could be topped up by individual contributions.⁴⁰ Finally, some participants felt that there needed to be an increased focus on prevention, such that more support was provided for people with moderate needs to ensure that such needs didn't escalate.⁴¹

There were mixed views on whether funding needed to be locally or nationally controlled. Locally controlled funding was perceived as potentially leading to greater innovation and a higher quality of service. It was also regarded as responding more effectively to local needs and providing greater flexibility. On the other hand, it was felt that nationally controlled funding would provide for greater consistency and be less complicated and more efficient.⁴²

Participants were split on whether there needed to be a single care system or whether there needed to be a separate system for older people and people of working age who are disabled.⁴³ Although there was consensus on the need for a single system in the 'inclusivity' consultation, participants also reported that the system needed to be flexible enough to provide for the different needs of both groups.

³⁵ Ipsos Mori (2008a)

³⁶ Wanless and Forder (2006)

³⁷ COI (2008a)

³⁸ Ipsos Mori (2008b)

³⁹ Ipsos Mori (2008a)

⁴⁰ COI (2008a, 2008b)

⁴¹ Ipsos Mori (2008b)

⁴² COI (2008a); Ipsos Mori (2008a)

⁴³ COI (2008a, 2008b)

4. Impact of the specific proposals outlined in the Green Paper on different equality strands

The specific reform proposals set out within the Green Paper fall under three broad headings:

1. *The vision for the future*

- Investing further in prevention services.
- Creating a national assessment to improve transparency, understanding and outcomes.
- Improvements to information, advice and advocacy services provided to individuals about the system.
- Furthering the personalisation agenda.

2. *Making the vision a reality*

- More joined-up service delivery.
- A wider range of care and support services.
- Better quality, more innovative services, based on the best evidence about what works.

3. *Funding options*

- Making the best use of existing funding.
- Bringing new money into the system.
- Accommodation costs.
- A nationally or locally determined funding system.

The proposals seek to promote greater diversity and equality and reduce any disadvantages within the current system. It aims to ensure that people feel more empowered, moving away from being just recipients of the system towards being active citizens, shaping the care they receive to help them live the life they want, wherever they live. The following sections consider the potential impact of the specific proposals suggested within the Green Paper on different groups based on available evidence and possible challenges for the future.

1. The vision for the future

Investing further in prevention services

The Green Paper proposals look at the further investment in the preventive agenda, which could have a beneficial impact on those people who currently have no care and support needs and those for whom prevention services will stop their existing needs from worsening. In terms of investment in further preventive interventions, one study has noted that shifting social care funding towards prevention could reduce the demand

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on acute hospitals so that 30 per cent spent on social care could be recycled from savings made in the NHS.⁴⁴

The reforms proposed aim to make some services, particularly re-ablement, more widely available, although some of the inequalities within the current system associated with support for people with low-level needs may to some extent remain.

If funds shift to prevention at the expense of funding support for people with high-level needs, this can have a negative impact on individuals with high-level needs. Therefore, while evidence-based prevention would be beneficial for low-level need groups, the system as a whole would need to ensure that an over-emphasis on prevention does not lead to an adverse impact on those with a higher level of need.

Impact on equality strands

Funding for lower level needs would seem to be particularly beneficial for older people and people from LGBT groups for whom these needs have great value.

Creating a national assessment

The local variation in the assessment criteria and process have led to a demand for a clearer, transparent and more consistent system. The Green Paper outlines proposals for creating a national assessment where everyone will be assessed in the same way, and once they have an agreement about their level of need, they will be able to take it with them wherever they go in England (i.e. it will be 'portable'). They will not need to be reassessed unless their needs change. This simple, nationally portable assessment seeks to ensure that there is more consistency within the current system.

Impact on equality strands

This would make it easier for disadvantaged groups such as older people, younger people in transition between services, ethnic minority groups, and LGBT groups to receive support that meets their needs. It would also provide clarity about whether or not one is eligible for support.⁴⁵ Findings highlight the tendency for some groups to refrain from accessing assessments as they do not believe they will receive the care they need. In terms of impact across equality strands, the Green Paper proposals towards introducing a more standardised national assessment could potentially lead to more people presenting themselves for assessment and thus possibly receiving the care they need, especially within the various equality strands previously identified as being disadvantaged by the current system.

Improvement to information, advice and advocacy services provided to individuals about the system

The Green Paper outlines a number of potential ways in which information, advice and advocacy services could be improved to ensure that people have a better understanding and awareness of how the system works and what support is available to

⁴⁴ Gainsbury (2007)

⁴⁵ CSCI (2008a)

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them to ensure that individuals and their families are better informed and best placed to make the right decision for them.

Impact on equality groups

The measure suggested within the Green Paper should help to improve the situation for all equality groups.

Furthering the personalisation agenda

Among other things, *Putting People First* stated that in the longer term everyone would have access to a personal budget. The Green Paper sets out a commitment to extend availability of personal budgets to every eligible person who wants one.

Impact on equality strands

Evidence on the current impact of personal budgets suggests that the main barrier to getting the most benefit from them, particularly for different ethnic groups, is the lack of culturally sensitive market provision. Therefore, in extending the personal budget approach we will need to ensure that greater cultural sensitivity is recognised, so that individual needs are appropriately met.

In terms of the likely financial impact of extending personal budgets, this would be beneficial to all equality strands given that they seek to promote greater choice and more control for individuals. The up-front allocation of resources based on need and reflecting local market conditions will, over the longer term, ensure that resources are distributed more equitably than currently.

This is likely to have a more positive impact on older people in particular, who, compared with other client groups, appear to benefit less from the current system. Additionally, reforms proposed within the Green Paper will help individuals to make informed decisions about their care through better risk management (to reduce the likelihood of exploitation) and increased access to advocacy services. This is particularly pertinent in the case of older people as it will ensure that, should they under-assess their needs, they will receive the level of care appropriate to their needs and reduce the possibility of their needs remaining unmet.

2. Making the vision a reality

Within the Green Paper, it considers to encourage more joined-up working, a wider range of care and support services and better quality, more innovative services, based on the best evidence about what works.

The aim of this is to ensure services are better joined-up working between health, housing and social care services and between the care and support and benefits systems. In addition, that people have greater choice over the care and support they receive, through a wider range of services to choose from and that services that are available are based on the best and most recent information about what works in providing care and support.

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Impact on equality strands

Overall, this is likely to have a positive impact on all service users. However, there is no evidence specifically of the impact on the various equality strands.

3. Funding options

Making the best use of existing funding

The Green Paper presents options around possible integration of some disability benefits, for example, Attendance Allowance, with social care funding to provide a more joined-up, consistent and fair care and support system. The aim of this is to create a new and better system, which would be simpler for all to use and access and focused on those most in need of support. As this would be a significant reform, any new care and support system would also be phased in over a number of years.

General impact on all recipients of disability benefits

Whatever the outcome of the consultation, we want to ensure that people receiving any of the relevant benefits at the time of reform would continue to receive an equivalent level of support and protection, under a new and better care and support system.

Drawing together some disability benefits, for example Attendance Allowance, within care and support would create a simplified, all-in-one assessment process for people with care needs. People would be able to access the support they need and their experience of the system would improve.

Some people – such as those with higher needs – who previously did not receive any state support would be better off, as targeting of support would mean that they would be entitled to some support under the new system (see the next section on bringing more money into the system). The exact impact on individuals will depend on the final design of the system.

Impact on equality strands

Current evidence highlights that at present:

- Ethnic groups, particularly Pakistani, Bangladeshi and Black African people are less likely to receive certain disability benefits than White British people. Evidence highlights five barriers to uptake among BME groups: personal resources, attitudes to claiming, social capital, external factors and macro factors, for example language barriers, concerns about the impact on residency status, not having a National Insurance Number (particularly for Asian women), literacy problems, ignorance about the benefits system, and apprehension about contact with statutory service providers.
- Some older people are less likely to apply for disability benefits as they see claiming as being 'like begging' and an admission of failure. They also place a high value on privacy, particularly in their financial affairs, making them reluctant to apply for

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benefits.⁴⁶ As some disability benefits such as Attendance Allowance are only for older people of retirement age, these barriers to uptake experienced by older people are especially pertinent in this case.

If it was decided to integrate any disability benefit into the overall care and support system, this may help improve the situation for those from BME groups as the new fully integrated system would be simpler for all to use and access. This may result in more applications from BME groups. However, these groups are often not in touch with social care and greater awareness would need to be created so that these groups would feel more comfortable to apply.

Bringing new money into the system

Green Paper options

The current funding system is funded through a combination of general and local taxation. State support from social care is provided to those who cannot pay for themselves and often this means that people who do not qualify for state support will have to fund their care themselves.

A number of funding options have been presented within the Green Paper. The options are set out below and they range from those where responsibility for the cost of care rests entirely on the individuals to those which place responsibility entirely on the state.

- 1) **PAY FOR YOURSELF.** In this system, everybody would be responsible for paying for their own basic care and support, when they needed it. They could take out insurance to cover some of these costs, or use their income and savings. There would be no support from the State even for people with the lowest incomes and no savings. This is ruled out because it would leave many people without the care and support they need, and is fundamentally unfair because people cannot predict what care and support they will need.
- 2) **PARTNERSHIP.** In this system, everyone who qualified for care and support would be entitled to have a set proportion - for example a quarter or a third – of their basic care and support costs paid for by the State. People who were less well off would have more care paid for – for example two thirds – while the least well-off people would continue to get all their care for free. The average cost of care for a 65 year old is £30,000, so someone who got the basic offer of a third or a quarter paid for might need to pay around £20,000 or £22,500. Many people would pay much less. And some people who needed high levels of care and support would pay far more than this, and would need to spend their savings and the value of their homes. This system would work for people of all ages.
- 3) **INSURANCE.** In this system, everyone would be entitled to have a share of their care costs met, just as in the Partnership model. But this system would go further to help people cover the additional costs of their care and support through insurance, if they wanted to. The state could play different roles to enable this. It could work more closely with the private insurance market, so that people could receive a certain level of income should they need care. Or the state could create

⁴⁶ DWP (2003)

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its own insurance scheme. If people decided to pay into the scheme, they would get all their basic care and support free if they needed it.

People could pay in several different ways, before or after retirement or after their death if they preferred. As an indication of the costs, people might need to pay around £20,000-£25,000 to be protected under a scheme of this sort, compared with the average cost of care for a 65 year old which is £30,000. This system would work for people over retirement age.

- 4) **COMPREHENSIVE.** In this system, everyone over retirement age who had the resources to do so would be required to pay into a State insurance scheme. Everyone who was able to pay would pay their contribution, and then everyone whose needs meant that they qualified for care and support would get all of their basic care and support for free when they needed it.

It would be possible to vary how much people had to pay according to what they could afford. The size of people's contribution could be set according to what savings or assets they had, so that the system was more affordable for people who were less well off.

Alternatively, if people wanted to be able to know exactly how much they would have to pay, most people other than those with lower levels of savings or assets could be required to pay a single, set figure, so that people knew how much they would have to save for.

As an indication of the costs, people might need to pay around £17,000 - £20,000 to be protected under a scheme of this sort compared with the average cost of care for a 65 year old which is £30,000. The cost would be less for people who were over 65 when the scheme was introduced. People could pay in several different ways, in instalments or as a lump sum, before or after retirement, or after their death if they preferred. Once people had paid their contribution they would get their care free when they needed it.

It would also look at having a free care system for people of working age alongside this.

- 5) **TAX-FUNDED.** In this system, people would pay tax throughout their lives, which would be used to pay for all the people who currently need care. When, in turn, people needed care themselves, they would get all their basic care free. This system would work for people of all ages. This is ruled out because it places a heavy burden on people of working age.

The following sections consider the impact of introducing each of these funding options on the different equality strands, concentrating particularly on the impact on individuals disposable income, given this is the focus of most of the evidence available.

1. Pay for yourself

The Green Paper has ruled out this option, given that this places sole responsibility for the full cost of care on the individuals who need it. Given that the number of people who may face very high costs of care in the future is growing, under this system, many

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people will be unable to afford these care costs and many more could lose everything that they have earned or saved in trying to cover these costs.

Evidence suggests that this option could negatively affect people with lower incomes, particularly some people in at least some of the equality strands, who would be unable to afford the cost of care, such as the following:

- **Older people** who had not been able to accumulate savings over their lifetime.
- **Disabled people**, specifically those with physical, learning and mental health impairments, are less likely to be economically active and so would be less likely to be able to contribute as they may have lower incomes and limited savings for future care costs that may arise.⁴⁷ For example, disabled men's gross weekly earnings reduced slightly from 83 per cent of non-disabled men's earnings in 1996/97 to 82 per cent in 2004/05, with a larger decrease among disabled women (which reduced from 87 per cent to 84 per cent of non-disabled women's earnings). In addition, issues of mental capacity may make people with mental health problems and learning disabilities less able to make decisions regarding funding and payment themselves.⁴⁸
- **Women:** Evidence suggests that gender differences in gross weekly earnings reduced in the period studied (1996/97 to 2004/05). However, when seen in light of the fact that women's educational levels increased more than men's, their earning levels became relatively worse over the period.
- **BME groups:** Evidence found that while education protects against disadvantage in employment and earnings, this is partial and relative – many people from ethnic minority groups, for example, experience poorer employment rates and lower incomes than white people, despite having high levels of education. For example, evidence highlights that all men from ethnic minority groups (other than those of Indian origin) earned significantly less than white men in 2004/05.

Given the evidence, it is unlikely that those from low-income groups would be able to afford the cost of care through savings or assets or through purchasing private insurance. Therefore, this option could lead to increased levels of unmet need as individuals would be unable to access the care that they need. This could also lead to an increased burden on informal care.

2. Partnership

If the system was reformed, whereby everyone is entitled to some support, this would have a positive impact on all individuals in need of care.

A guaranteed entitlement to some state care would probably be most beneficial to older people as they are more likely to be 'savers' who are currently penalised by the system. Older people would also benefit from reforms that make the means-testing criteria more transparent as its current complexity can act as a deterrent to seeking help.

Furthermore, since the evidence indicates that the number of people self-funding their care has been rapidly increasing due to higher costs and tighter eligibility criteria, an

⁴⁷ COI (2008)

⁴⁸ COI (2008)

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entitlement to some state care would have a positive impact on all equality strands. In particular, younger and older disabled people who are currently penalised, for example those with assets or pensions,⁴⁹ could benefit from this reform, as they are currently likely to face high costs. The benefit to the lowest income group and those with no assets would be the least, as they already receive, and would continue to receive, 100 per cent of the cost of their care.⁵⁰

Additionally, this option may benefit those from BME and faith groups, as evidence highlighted that there were high levels of concern among some of these groups about the idea of releasing equity from homes to pay for care, feeling it was the right of the individual to leave an inheritance to his or her family members. This option provides these groups with greater protection of their inheritance, as they will have to contribute less towards their care.

3. Insurance (private or state-backed insurance)

This option would have the same benefits as the partnership option above. In addition, this model provides the option to cover the remaining cost of care through insurance (either private or state-backed insurance, depending on the option selected.)

For those who chose to take out the additional cover, (either the private or state-backed insurance, depending on which option was implemented) this would have a positive impact. Individuals from all equality groups who purchased the cover would have all of their basic care costs covered. However, those who choose not to enter the system (particularly those unable to afford the insurance premium) may still experience some unmet need, although this would be reduced given the fact that some of their care costs would be covered.

This option may benefit BME and faith groups specifically, as it provides these groups with greater protection of their inheritance, with the choice to protect more of their inheritance through insurance.

4. Comprehensive

This option would cover all of their basic care costs (for all those eligible).

The impact across equality strands would probably be most beneficial to those groups of people who are currently penalised by the system – i.e. those with assets or pensions,⁵¹ such as older people, as they are more likely to be ‘savers’. Older people would also benefit from reforms by removing means testing at the point of need, as the system would be more transparent as its current complexity can act as a deterrent to seeking help. Furthermore, since the evidence indicates that the number of people self-funding has been rapidly increasing due to higher costs and tighter eligibility criteria, a guaranteed entitlement to state care would have a positive impact on all equality strands. In particular, BME and faith groups would benefit as this option also offers these groups greater protection of their inheritance as all their basic care costs will be covered.

⁴⁹ CSCI (2008b)

⁵⁰ Hancock et al (2007)

⁵¹ CSCI (2008b)

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The benefit to the lowest-income group and those with no assets would be the least, as they already, and would continue to, have all of their care funded.⁵²

5. Tax-funded

This option would have the same benefits as the Comprehensive option. However, this would require a significant increase in the tax that people already pay, because taxation would be funding all of care and support, including the parts the people currently pay for themselves when they need it. For this reason we have ruled out this option.

A nationally or locally determined funding system

Part local, part national

Under this system, there would be nationally transferable (portable) assessments. National government would set the threshold for which someone was eligible for state support. Therefore, if a person has a certain level of need they will be eligible to receive funding to meet their care costs. However, local authorities would still decide for themselves the monetary amount of care they were going to provide at each level of need.

Impact on equality strands

This option would have a positive impact on all equality groups and in particular disabled people for the following reasons:

- It enables disabled people to know, before they move somewhere, what level of support they would be entitled to in the new area. However, funding levels will depend on how much money a local authority wants to spend on care and support. Therefore help could vary depending on where someone lives, which means that a person would not be able to take their cash entitlement with them.
- Local authorities would still decide for themselves the amount of support they were going to provide at each level of need. This allows local authorities to cater for variation in the local care market and to more accurately cater for individuals' needs.

Fully national

Under this system, national government would decide how much funding people should get, instead of local authorities. We could set up a system where everyone who had the same level of need received exactly the same funding wherever they lived in England, but this wouldn't take account of the fact that the same amount of money will buy fewer services in one area of England as compared to another. Or we could have a national system that gave people slightly different amounts depending on where they lived in England to take account of the different costs of care across England.

Impact on equality strands

⁵² Hancock et al (2007)

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This option would have a positive impact on all equality groups and in particular on disabled people.

- This system would be easy for people to understand and plan for as they would know exactly what state support they would be entitled to, wherever they live.
- Everyone with the same care and support needs will get the same level of support.
- Portability between localities would give citizens more opportunity to move and more certainty about the support they will receive.

However, there could be some negative impacts on equality groups as national government would may not be to as accurately take account of the variations in local care markets and individuals' needs, as well as a locally determined amount. It would also make it more difficult for local authorities to tailor the care packages people receive to their wishes and to respond to local circumstances.

Accommodation costs

Although the state would contribute towards the cost of care within residential care, there still may be some costs which the individual may have to pay. In addition, accommodation costs for residential care will have to be covered by the individual if their assets are above the threshold eligible for full state support. In a bid to ensure that nobody is forced to sell their house in order to cover their residential costs during their lifetime, the Green Paper outlines proposals to extend the option of deferred payment schemes (already available to some by their local authority) making it universal and available for all, so individuals can defer payment of care and accommodation costs until after death.

Impact on equality strands

There is limited evidence to suggest that this reform will have any significant impact on equality strands. However, this reform does give individuals and their families peace of mind in knowing that they have different options. Under the current system, individuals may have had to sell their homes to pay for the cost of residential care whereas, as a result of reforms, more individuals will have the choice to defer payment until after death. This means people do not have the hassle of selling their homes, particularly at what can be seen as an emotional time. It also allows more people to stay in their own homes for longer.

Carers

Although the presence of a carer would still be recognised under a reformed system, changes to the overall funding system discussed previously could also help to reduce the burden on some informal carers. Under all the National Care Service models, everyone who is eligible would be entitled to some support towards their care, regardless of their means. This could mean that some people who had previously received no funding from the state could now receive this support, which could reduce the level of informal care that they may require. Under the Comprehensive model, all individuals eligible for support would receive all their basic care and support for free at the point of need.

5. Summary of the main messages on the impact of reforms on different equality strands

This section summarises the key messages arising from the likely impact of the reforms being considered with the Green Paper on the different equality strands and some of the challenges that may arise.

Age

- Extension of personal budgets may positively impact older people. Reform of the system will improve risk management to reduce the likelihood of financial exploitation and increase access to advocacy in order to ensure that, if they under-assess their needs, they receive the care they are entitled to. This would also help reduce the possibility of unmet needs among older people.
- Reform of the funding system will have a positive impact on younger and older people who are penalised under the current system, for example those with assets or pensions⁵³ who therefore receive no state support towards their care costs. Under the new system, they will be entitled to have at least part or possibly all their care costs covered (depending on which option is chosen) therefore reducing the amount they may need to pay privately.

Gender

- Changes to the funding system would mean that women in particular would benefit as they would be entitled to a degree of state care which, given the fact that care costs for women tend to be higher, could help to reduce the cost of care for women, particularly those who currently self-fund their entire care. In addition, given the fact that women are mostly likely to purchase insurance at present, the cost of insurance would be lower than the expected lifetime costs they could face at 65, as some of their care costs under a new funding system would be covered by the state.

Disability

- Extension of the personal budget approach would have a positive impact on quality of life outcomes as a result of greater choice and flexibility, particularly for people with mental health problems and other disabilities.
- Creating a national assessment process would have a particularly positive impact on young disabled people as this will allow them to move around more freely (particularly as many may choose to move to seek employment and are unable to do so under the current system). The new assessment process will be clearer, standardised and portable in that individuals will know what level of support they would be entitled to in a different local authority, making it easier to move around more freely.
- In addition, as national government would now set the threshold for which someone was eligible for state support, this means that people with a certain level of need will receive funding to meet their care costs wherever they live. However, depending on how funding will be determined in the future, local authorities could still decide for themselves the monetary amount of care they were going to provide at each level of

⁵³ CSCI (2008b)

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need. But unlike the current system, disabled people would still know, before they move somewhere, what support they would be entitled to in the new area.

Sexual orientation

- Personal budgets are seen to have great potential in delivering personalised care that meets the lifestyle and cultural needs of LGBT people – e.g. employing a care worker who is also gay. Extension of the personal budget approach will have a positive impact on this group. However, LGBT users report experiencing difficulties recruiting suitable care workers (who understand and respect their specific needs) due to lack of available staff. Therefore, one challenge will be to ensure supply of staff within the care market is tailored to those who need it.
- Reform of the assessment process, in particular the way carers are considered within the new system, will need to ensure that the definition of ‘carers’, which usually defines them as family members, recognises that for LGBT people the term ‘family members’ is more broad, and that carers are often friends or partners of the individuals in need.

Faith or belief

- Very few of the studies reviewed looked at specific issues relating to the impact of social care on faith groups. One of the few exceptions found that there were high levels of concern among some religious groups about the idea of releasing equity from homes to pay for care, feeling that it was the right of the individual to leave an inheritance to his or her family members. The preferred funding options provide these groups with greater protection of their inheritance, with the choice to protect more of their inheritance through insurance.

Race

- Personal budgets are seen to have great potential in delivering personalised care that meets the lifestyle needs of BME groups, as it allows them flexibility to acquire the care they need according to cultural requirements. Extension of this approach will have a positive impact on these groups.
- Improved consistency of needs assessment, better information and advocacy, and a simpler and more transparent funding system would have a positive impact on people from BME groups, as the complexity of the present system often hinders these groups from seeking the support they need due to lack of information and inability to access the system. A simpler system may result in more applications from BME groups. However, these groups are often not in touch with the care and support system and greater awareness would need to be created so these groups felt more comfortable to apply.
- In addition, a new standardised assessment process will need to take better account of cultural sensitivities.

Rurality

- There was some evidence with regard to the possible challenges faced by people living in rural areas. In particular, recruitment of care workers in rural areas is problematic and constraints on workforce supply include limited access to transport, low wages and a lower pool of suitable applicants. With greater emphasis on ensuring a wider range of care and support services available, that meet the needs of the local area it serves, this should help to improve the supply of care in these areas to ensure that it is tailored to those who need it.

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Human rights

- By giving people greater control over choosing carers and support, personal budgets can help to ensure support that is tailored to the needs of the individual.
- However, in the case of older people who may be less confident or face communication difficulties, potential problems need to be identified at an early stage of the support process and appropriate safeguards put in place to prevent negligence and abuse. There may be particular concerns where care is provided by close family members or friends who are not subject to regulation and inspection. The reforms proposed will provide additional support to older recipients of personal budgets, including better risk management (to reduce the likelihood of exploitation) and increased access to advocacy, which should help to mitigate some of these problems.

Overall, all reforms proposed within the Green Paper, seek to promote a care and support system which is underpinned by the principles of greater equality within the system and where diversity of users and what they require from the system is recognised, to ensure that people have choice and control in terms of the support they receive so that it is tailored to their needs.

6. Recommended actions

Based on the findings of this EIA, there are further areas of work which need to be taken forward as part of the process of considering potential reforms of the care and support system. Further research and data analysis will need to be undertaken to better understand the impact of specific proposals.

The forthcoming public consultation process following publication of the Green Paper will provide a good opportunity to engage with key groups representing the different equality strands to understand the issues around what the reforms will mean for these specific groups.

7. Methodology for research

This section outlines the methodology behind the research collated by the Office of Public Management on behalf of the Department of Health. A systematic approach to collating and reviewing the relevant literature available from a large number of academic and other databases was used. An initial search was made to identify candidates for inclusion. These were then prioritised in terms of their relevance to the key lines of enquiry established by the Department of Health, taking into account other criteria including date of study and robustness of evidence.

A full list of the documents reviewed is included in the EIA. The majority of sources were published in the last two or three years and include studies commissioned by government agencies (e.g. the Commission for Social Care Inspection and the Equality and Human Rights Commission), independent research organisations (e.g. the Joseph Rowntree Foundation and The King's Fund), academics and government departments themselves.

The studies reviewed based their findings on a wide range of quantitative and qualitative evidence, generated using methods including: in-depth telephone interviews and case studies, with service users, professionals and experts; literature and policy reviews (including international comparisons); reviews of inspection and assessment data; surveys; and statistical modelling.

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