



**For better
mental health**

Shaping the future of care together The Government's Green Paper on social care

Response from Mind

About Mind

Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.

The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.

Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.

We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.

We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

Introduction

Mind welcomes the publication of the Green Paper and the opportunity to participate in a timely and much-needed debate about the future of social care in England. Social care services are vital to managing long term mental health problems and to preventing crises, as well as supporting recovery, social inclusion and independence for people with lower level needs. It is therefore essential that mental health is not a secondary consideration in the development of any new system.

We warmly welcome the overall vision in the Green Paper of a National Care Service rooted in prevention, national assessment, personalisation and joined-up services. These features were all recommendations made by Mind during the pre-consultation phase in 2008.¹

¹ Mind (2008) *Reform of the care and support system: Response from Mind*.

We are concerned that the Green Paper does not address the considerable barriers to accessing care and support which many people with mental health problems face now. As well as articulating a long term vision for a social care system which better serves the needs of users, there is an urgent need for the Government to take short and medium term action to increase access to a wider range of preventive social care services. This will prove more cost-effective for Government and local authorities in the long run, based on a global cost-benefit analysis.

Alarming, the Green Paper is largely silent on mental health, and only mentions adults with disabilities in passing. This is a glaring omission given the importance of social care services for helping many people with mental health problems to stay well and live independently in the community. The absence of consideration of mental health is emblematic of the wider debate around social care, which has tended to be skewed towards older people. Mind recognises that, due to demographic change, older people are likely to be the fastest growing group of people requiring care and support in the future, with significant cost implications for both individuals and the public purse. Regrettably, these pressures have led to the development of funding models, set out in the Green Paper, which only appear to have been modelled around the needs of older people. The Green Paper leaves many questions unanswered about how the funding options might affect adults of working age with disabilities, particularly fluctuating mental health conditions.

In establishing a National Care Service that is 'fairer, simpler and more affordable for everyone', the Government must develop further its plans for disabled adults of working age, in terms of both service provision and finance.

This response sets out Mind's concerns about the Green Paper, in relation to each of the three consultation questions. Mind's position is informed by extensive consultation with our networks of people with mental distress. Detail of our methodology is at Appendix A, and any unattributed quotations in the response are from people with mental health problems who use social care services.

Mind has also submitted a short response in partnership with other mental health organisations, Rethink, the Sainsbury Centre for Mental Health and the Mental Health Foundation. Mind is a member of the Disability Charities Consortium, which has submitted a complementary response that we fully endorse.

Mind's recommendations

	The Government should	Timescale
1	Develop detailed proposals and modelling about how a National Care Service would guarantee the six principles in practice, and how the NCS and NHS would operate effectively together, to be consulted upon before the White Paper is published.	URGENT
2	(a) gather best practice of prevention services which work for adults of all ages, particularly those with mental health problems, (b) articulate these in any future proposals for a National Care Service, and promote the dissemination of these examples to local authorities.	Within 6 months
3	Clarify what level of need disabled people will be expected to meet in order to qualify for state support for social care.	URGENT
4	Overhaul the four-tier structure of the FACS eligibility criteria as a priority as part of any future reform of social care.	Within 6 months
5	Conduct a broad cost-benefit analysis across public services in order to invest in more affordable, subsidised social care for people with mental health problems.	Within 6 months
6	Produce guidance to local authorities instructing them to base spending decisions at local level on global cost-benefit analysis, which will illustrate the case for investment in prevention over crisis management eliciting cashable savings in the medium to long term.	Within the next year
7	Ensure a new national assessment framework reflects and responds to the circumstances of people with fluctuating conditions whose needs change over time.	Within the next year
8	Clarify its proposals for a new national assessment framework, particularly around eligibility thresholds in terms of both care needs and ability to pay.	URGENT
9	Ensure better information resources are accompanied by training and guidance for frontline staff on the importance of providing advice coupled with user involvement.	Within the next year
10	Embed, and fund, universal advocacy, information, advice and brokerage, which are a prerequisite to take up of personalised approaches.	Within 6 months
11	Provide strong national leadership on personalisation, which includes encouraging professionals to take positive risks.	Within 6 months
12	Ensure a new National Care Service adopts a broad definition of care and support, including support for managing money and support for engaging in community activities, maintaining independence, mental health and wellbeing.	Within 6 months
13	Ensure: (a) people who wish to do so are allowed the right to access traditional models of support (rather than pushed to receive support through a direct payment), and (b) new services are nurtured, and existing service providers are supported to evolve.	Within 6 months

	The Government should	Timescale
14	Building on the 'Link Up Link In' initiative, conduct a thorough, country-wide analysis of best practice in joined-up service provision, by both statutory agencies and voluntary organisations.	Within 6 months
15	Ensure best practice informs the development of proposals on social care and future guidance for local authorities on how to base investment decisions on cost-benefit analyses across health and social care and other public services.	Within 6 months
16	Look at ways to revise local level delivery mechanisms and bring into line different outcomes frameworks to foster joint-working.	Within the next year
17	Bring personalisation programmes like Right to Control and Individual Health Budgets together to be delivered as one single service.	Within the next year
18	Ensure the new guidance issued following the FACS review (a) restates using CPA as a screening tool for eligibility is unlawful (b) instructs local authorities and PCTs to conduct joint health and social care assessments for potential service users, and joint decision making and budget setting for preventive services.	Within 6 months
19	Reconsider both the economic and equity benefits of a funding option including general taxation or national insurance contributions.	URGENT
20	Produce far more detailed modelling on how the three funding options would work in practice for adults of all ages with different needs, followed by further consultation on these options.	URGENT
21	Ensure that any future funding system does not have a further negative impact on people with mental distress, who are already a disadvantaged group in society.	Within 6 months
22	Clarify, with detailed modelling, how a free system for people under 65 would work alongside the Comprehensive model.	URGENT
23	Not adopt a funding system based on private insurance, as such an option would discriminate against people with mental health problems, if they were expected to contribute.	Within 6 months
24	Retain Disability Living Allowance for over 65s, as well as under 65s, and Attendance Allowance for all.	URGENT
25	The Government should carry out further modelling of how a national system, where the national assessment process is linked to the amount of funding allocated to an individual, would work in practice, particularly around the tension between locally and nationally raised taxation.	URGENT

Consultation question 1:

We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- ***prevention services***
- ***national assessment***
- ***a joined-up service***
- ***information and advice***
- ***personalised care and support***
- ***fair funding.***

a) Is there anything missing from this approach?

b) How should this work?

Mind agrees with the six principles that should underpin a future National Care Service. These features are essential if any future social care system is to work more effectively for people with mental health problems. It would be useful to know more about how these six principles will be realised, and how the National Care Service would dovetail with the NHS. We set out our specific concerns below under each of the six principles. Mind would be delighted to discuss these issues further with the Department of Health, before the White Paper is published.

Mind's recommendation:

- (1) The Government should develop detailed proposals and modelling about how a National Care Service would guarantee the six principles in practice, and how the NCS and NHS would operate effectively together, to be consulted upon before the White Paper is published.**

1.1 Prevention services

“Prevention is better than treating the symptoms, which is very expensive. Like putting ambulances at the bottom of a dangerous cliff instead of erecting a fence at the top.”

Mind supports the Government's commitment to providing prevention services. Currently social care services are directed primarily at crisis management and most local authorities only provide services to those with high level needs. The Government has recognised this approach is flawed and the draft guidance on the Fair Access to Care Services (FACS) eligibility criteria explicitly calls on local authorities to shift investment to prevention services.²

There are a number of contradictions in the Green Paper's articulation of how prevention services might work in social care, which are of concern to Mind. In a number of places 're-ablement' seems to be used synonymously with 'prevention'. While we welcome the proposals for six weeks re-ablement care when people are leaving hospital, this measure does not amount to a wholesale shift towards a prevention, rather than crisis management model of care and support. This is early

² Department of Health (2009) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care.*

intervention or recovery, not prevention. We are concerned that the re-ablement focus is geared towards older people and based on the medical model of disability. Similarly, the examples given in the Green Paper of what prevention services might look like (Telecare, housing adaptations) are focussed on older people's needs. There is no mention of services which promote the wellbeing and independence of people with mental health problems and prevent crises. While we welcome the suggestion for an independent body to research and model different types of prevention services and advise on what works, this will take time to establish. The Government should act now to encourage and promote existing best practice in prevention services.

Case study: prevention and wellbeing

Joan³ has schizoaffective disorder and uses social care services to keep her well and out of hospital. A support worker visits her for two hours per week, to help with managing things in the flat and to accompany her shopping and to appointments. The support is very flexible and Joan can request more or fewer contact hours as and when she needs them.

"I find the service very helpful, I mean, it's different to when I used to have home help, because the idea is that I don't just lie around and they do everything for me, but that we do it together and also with this most recent worker I had, we'd chat a lot and that so it was a wider form of support as well."

Joan also gets support to study for a part-time Masters degree and until recently attended a print-making class funded by the local authority. She is currently part of a 'buddy' scheme where a volunteer goes walking with her weekly to help build her stamina and fitness, so she can join a healthy walking group which will help her recovery.

"It just enables me to cope really and get into some kind of system in the flat and my daily life [...] it keeps me at home longer in the community than would ordinarily be the case."

Mind's recommendation:

(2) The Government should

- (a) gather best practice of prevention services which work for adults of all ages, particularly those with mental health problems,**
- (b) articulate these in any future proposals for a National Care Service, and**
- (c) promote the dissemination of these examples to local authorities.**

Mind is also concerned that there is a tension between the stated commitment to prevention services and the reality of squeezed budgets given the difficult economic climate. In an interview, Mind heard how one service user was refused access to an art therapy evening class, costing just £80 for the winter term, because she was already on a vocational training scheme: "[My social worker] says well you can't have anything else until I've finished my 'workwise' which finishes at Christmas." At present many disabled people are denied care and support services altogether, because they do not meet the FACS eligibility criteria. People with mental distress, in particular, often fall under the 'low' or 'moderate' FACS bands, which are not provided with local authority funded care. Depending on where the threshold is set in

³ Names have been changed to preserve anonymity.

any new system there could be serious implications for people with lower level needs who still require support to live independent lives.

Reluctance to deliver low level prevention services is disclosed in the Green Paper's statement that everyone will get help with 'high-level' care costs, which seems to contradict commitment elsewhere in the document to supporting those with low level needs to stay well in the community. The Government must clarify exactly what level of need disabled people will be expected to have in order to qualify for state support.

Mind's recommendations:

- (3) The Government should clarify what level of need disabled people will be expected to meet in order to qualify for state support for social care. This eligibility threshold should reflect the Government's stated commitment to prevention services and set the bar accordingly.**
- (4) The four-tier structure of the FACS eligibility criteria should be overhauled as a priority as part of any future reform of social care. Mind has already made comprehensive recommendations on this in our response to the FACS review.⁴**

Mind is concerned that the proposals outlined are based on an assumption that people's needs and conditions are permanent, and ignores the reality that mental health problems can be overcome or prevented. People with bipolar disorder, severe depression or schizophrenia may have periods where they experience few or no symptoms and are able to manage without care and support. A modern system must adapt to the specific challenges posed by mental distress. Funding decisions in social care have an impact on spending elsewhere in the system. There is a strong economic argument for providing affordable, subsidised social care to people with fluctuating needs: the increased economic contribution that could be made by this group if they are supported to live independent lives, potentially return to work, and avoid the need for costly acute health interventions. For mental health specifically, the care budget cannot be disentangled from the benefits bill, employment rates and health spending. Mind is concerned that these wider cost-benefit arguments are still not reflected in the Government's care and support debate.

Mind's recommendations:

- (5) To realise its vision of a National Care Service rooted in prevention services, the Government should conduct a broad cost-benefit analysis across public services in order to invest in more affordable, subsidised social care for people with mental health problems.**
- (6) Guidance to local authorities should instruct them to base spending decisions at local level on global cost-benefit analysis, which will illustrate the case for investment in prevention over crisis management eliciting cashable savings in the medium to long term.**

1.2 National assessment

"Social services [should] do away with their criteria method of assessing people's needs and listen to the individuals and make a judgement from what they hear from that individual."

⁴ Mind (2009) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care*

“We have to overcome so many hurdles including *criteria* and we are often unable to cope with the stress of the battle ... if only we could have got help at a much earlier time, then the battle would not seem so hard.”

“I work full time, but because of this am discriminated [against] as being fully able; I'm not fully able all the time and could really do with being able to shout for a hand sometimes!!”

“I get psychotic very quickly – within a few days – so a fast response is vital.”

Mind welcomes the proposals for a national system of assessment and entitlement. However, as they stand, the proposals will not address the ‘postcode lottery’ in social care services. While people will get the same proportion of care costs covered wherever they live, they will still not receive the same budget, meaning the system will continue to offer different support to someone moving between local authority boundaries. As the Green Paper states, the national assessment does not guarantee that people have access to the same kinds of services. There is merit in enabling local authorities the flexibility to provide services tailored to the needs of their particular area. However, this also gives local authorities the option to cut service provision for other reasons, such as the need to balance squeezed budgets. This has led to the current situation where in some areas people with moderate or low level needs can access social care, while in a neighbouring authority people with substantial needs are being threatened with losing their support. This can be very distressing to people who move home and have their services withdrawn but it is also a wider issue about health inequalities up and down the country. The Government should consider further how it can link national assessment to local funding allocation (see question three below.)

There is no mention of how the assessment process might work in practice, particularly in terms of thresholds – relating both to needs and ability to pay – as well as how the assessment would take account of fluctuating needs. People with severe depression, bipolar disorder or psychotic illnesses such as schizophrenia may have periods where they can live very independently and experience few or no symptoms. Equally, there may be periods where the same person’s mental distress is extremely debilitating and has a serious effect on their ability to look after their health and welfare and that of their family. Currently, assessments, eligibility criteria and services are not designed to respond quickly to changing levels of need or to provide a service that is flexible over time.

Mind’s recommendations:

- (7) A new national assessment framework must reflect and respond to the circumstances of people with fluctuating conditions whose needs change over time.**
- (8) The Government should clarify its proposals for a new national assessment framework, particularly around eligibility thresholds in terms of both care needs and ability to pay.**

1.3 A joined-up service

Mind supports the stated commitment to joined-up services, but we are unclear how the broad statements in the Green Paper will be translated into real change in service

provision, with better outcomes for users. There are currently huge barriers to joined-up services, as we detail under question two.

1.4 Information and advice

Mind's research has identified the lack of adequate information and advice as a key barrier for people with mental health problems to accessing social care services, so we welcome the Government's commitment on this. The list of types of information needed (p. 56) is appropriate, but simply producing more information resources will not be sufficient. There needs to be a culture change among health and social care professionals towards user involvement – giving people all the necessary information and helping them to take educated decisions about what services will meet their needs.

Mind's recommendation:

(9) Better information resources should be accompanied by training and guidance for frontline staff on the importance of providing advice coupled with user involvement.

1.5 Personalised care and support

Mind welcomes the commitment to personalised care and support. People with mental distress should have equal access to the benefits offered by personalisation, but there are a number of barriers to be overcome if personalisation is to work well in mental health. Mind is currently leading Putting us First, a Department of Health funded project to increase uptake of personal social care budgets in mental health.⁵ The learning from that project, and more generally from the experience of personalisation in social care, should be embedded in future decision-making in mental health and social care policy. Mind would be happy to provide copies of the publications produced so far for the project.⁶

People with mental health problems have been slower than other disability groups to enjoy the benefits of personalisation in social care. The most recent figures suggest that today, around 3,500 people with mental health problems use a direct payment for their social care needs - far fewer than other groups.⁷ Our evidence suggests that the transformation of mental health services has encountered more challenges and generated more resistance from professionals than in other sectors. The key issues that have been identified include:

- The difficulty, in mental health, of separating out what is a mental health need (paid for by NHS money) from social care and other support needs
- How to manage personal budgets for people with fluctuating needs
- Concerns over the risks which might be posed by giving people control over their care and budget
- Lack of awareness and resistance by care coordinators creating a barrier to uptake.

⁵ For more information about the Putting us First project, visit:

http://www.mind.org.uk/campaigns_and_issues/policy_and_issues/social_care_services/putting_us_first

⁶ Mind (2009) *Personalisation in mental health: A review of the evidence*; Mind (2009) *Personalisation in mental health: Creating a vision. Views of personalisation, from people who use mental health services*; Mind (2009) *Personalisation in mental health: Breaking down the barriers. A guide for care coordinators*.

⁷ CSIP (2001-8) *NIMHE National Social Inclusion Programme: Direct Payments. Analysis of CSCI figures for direct payments used in lieu of adult mental health services*.

Our learning suggests that many of the barriers identified in social care might be avoided in the further implementation of personalised approaches, if appropriate infrastructure is made available from the outset. For example, the lack of investment in advice, advocacy and brokerage in social care has severely hampered progress. National investment in these universal services in advance of implementation is necessary for personalised approaches to bed in quickly, effectively and with minimal risk to service users. Another key barrier to implementation of personalisation in mental health has been the huge culture change that is needed, to put service users at the centre of their care and allow people to take positive risks. There is a pressing need to change professional cultures and assumptions about people with mental health problems (and other disabled people).

Mind's recommendations:

- (10) To realise the aim of providing personalised care and support in a new National Care Service, the Government must embed, and fund, universal advocacy, information, advice and brokerage, which is a prerequisite to take up of personalised approaches.**
- (11) There must be strong national leadership on personalisation, which includes encouraging professionals to take positive risks.**

1.6 Fair funding

Mind naturally supports the commitment to fair funding. However, the funding models proposed in the Green Paper are potentially not 'fair', or indeed workable, for adults of working age, particularly people with fluctuating mental health conditions. We outline our concerns under question three.

Consultation question 2:

We think that, in order to make the National Care Service work, we will need services that are joined-up, give you choice around what care and support you get, and are high quality.

- a) Do you agree?***
- b) What would this look like in practice?***
- c) What are the barriers to making this happen?***

A new National Care Service must be underpinned by joined-up services. It is therefore concerning that the Green Paper fails to reference other Government policies which are in development, such as the New Horizons consultation on the future of mental health services⁸ and the review of FACS eligibility criteria⁹. If policy is not joined-up at the highest level, it is difficult to expect services to be joined-up on the ground.

The Green Paper explicitly offers little narrative on how the new system will be designed or might work in practice (p. 65). It is very difficult to comment on such broad commitments – and particularly hard to make judgements about what funding will be necessary – without some understanding of how the Government envisages a

⁸ Department of Health (2009) *New Horizons: Towards a shared vision for mental health*

⁹ Department of Health (2009) *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care.*

National Care Service being structured. Although several examples of good practice are set out, there is no analysis of how these might be emulated in a coherent and consistent way across the country. Mind is further concerned that none of these good practice examples focus on services for people with mental distress.

2.1 Choice of services

Choice is an essential part of the move to personalisation in social care. As we outlined in section 1.5, there are considerable barriers to accessing personalised care and support for people with mental distress. These need to be overcome before a National Care Service can provide real choice for people with mental health problems.

From our research we know that people's concept of support extends beyond the health and social care sectors. For people with mental distress, social inclusion services such as art or music therapy, befriending schemes or support to engage in community activities, as well as public services like benefits advice, housing support and employment support, are equally, if not more important than traditional social care services. A National Care Service rooted in choice and personalisation must adopt a wider definition of what constitutes social care services, to encourage agencies to work together to provide holistic, person-centred packages of appropriate care and support. At the same time, some people with mental distress still prefer to access traditional modes of support, such as home visits or day centres. 'Choice' must not mean these services are phased out and everyone is required to take up a direct payment.

Mind's recommendations:

- (12) A new National Care Service should adopt a broad definition of care and support, including support for managing money and support for engaging in community activities, maintaining independence, mental health and wellbeing.**
- (13) To make choice a reality in social care, the Government should ensure:**
 - (a) people who wish to do so are allowed the right to access traditional models of support (rather than pushed to receive support through a direct payment), and**
 - (b) new services are nurtured, and existing service providers are supported to evolve.**

Case study: integrated community services

The Sunlight Development Trust, a social enterprise in Gillingham, has transformed a local building to meet the needs of all the community, rather than providing day services to segregated groups, such as people with mental health problems. They provide a range of services, including health, legal and debt advice, adult and youth education, employment support, a café, a recording studio – and, crucially, many of these services are developed and run by service users themselves. The success of Sunlight lies not necessarily in the particular services it provides, but in harnessing the benefits of integrating these services, so people have a 'one stop shop' to access the support they require, which is also somewhere they mix with other people of different experiences, backgrounds and needs.

Sunlight is an excellent example of providing integrated social inclusion services focused on prevention. It also demonstrates the benefits of designing services based on a global cost-benefit analysis, as many of the people who use and work at

Sunlight no longer need to access costly social care services from Medway Council, because their support comes from their employer, colleagues or other service users. Low level services like these can be important in preventing mental distress, encouraging social inclusion and maintaining wellbeing in the community. Services aimed at people with lower level needs will make savings for the NHS, and for the state as a whole.

The Government already has a resource of case studies and best practice which the Cabinet Office has gathered as part of its 'Link Up Link In' initiative to promote joint service provision for socially excluded adults. These examples should be drawn on in further development of the vision for a National Care Service.

Mind's recommendations:

- (14) Building on the 'Link Up Link In' initiative, the Government should conduct a thorough, country-wide analysis of best practice in joined-up service provision, by both statutory agencies and voluntary organisations.**
- (15) Best practice must inform the development of proposals on social care and future guidance for local authorities on how to base investment decisions on cost-benefit analyses across health and social care and other public services.**

2.2 Barriers to joined-up services

"A total lack of co-ordination and communication between [housing services, community mental health teams and other mental health services] is what caused my breakdown. They all insisted on working independently of each other when it came to my care and would pass the buck of a problem onto 'another department' and wash their hands of the fact that I was heading for a breakdown."

"I had to fight to get access to social services. My CBT [cognitive behavioural] therapist made a referral, but it was turned down with no proper explanation as to why. As a result, he found himself having to undertake a social worker role ... filling in DLA forms, writing housing references etc. He was unable to do his CBT as a result. Moreover he was my allocated care-coordinator despite not knowing where to access any of the care that was needed. ... Neither social services or my CBT therapist, who was supposed to be my care coordinator, had much knowledge of other local services."

To realise the vision of a choice of high-quality care and support, considerable barriers to joined-up service delivery across different agencies need to be overcome. The testimonies above identify some of the common problems encountered by service users and their support workers in trying to negotiate the minefield of different service providers. Joining up services is particularly important for mental health. Mental health problems do not neatly fit into "health" issues and "social care" issues, yet there is too often poor integration between health and social care services.

A key barrier is that delivery mechanisms for joined-up working are highly fragmented. At present different agencies work to very different outcomes frameworks, which makes joining up very difficult. For example, NHS, social care and housing services all have different performance targets which range from functional outcomes to much more citizenship focused outcomes. Closely related programmes

like the Right to Control trailblazers, Individual Health Budget Pilots, and the roll out of direct payments in social care are not joined-up and therefore do not support a holistic, person-centred service.

Mind's recommendations:

- (16) The Government should look at ways to revise local level delivery mechanisms and bring into line different outcomes frameworks to foster joint-working.**
- (17) Personalisation programmes like Right to Control and Individual Health Budgets should be brought together and delivered as one single service.**

In respect of the relationship between mental health and social care services, in particular, the differences in service funding and delivery are arbitrary and unhelpful for people with mental health problems. Community mental health services are informed primarily by clinical priorities and led by NHS budgeting priorities. Mental health services are not proficient at capturing local authority finance for social care, so care planning for the health and social care needs of a person with mental health problems can be completely absent of social care components. In fact, since the NHS is usually the first port of call for those needing mental health care, many potential service users are wrongly screened out before they can be assessed for social care because their clinical needs are not acute enough to engage with the health service. Equally, because the route to social care is concentrated within the community mental health service, many people who are treated solely in primary care are never assessed for social care needs because professionals anticipate they would not be eligible for free care, or because the Care Programme Approach is being unlawfully used as the gateway to social care services.¹⁰

Mind's recommendation:

- (18) The new guidance issued following the FACS review should**
 - (a) restate that using CPA as a screening tool for eligibility is unlawful,**
 - (b) instruct local authorities and PCTs to conduct joint health and social care assessments for potential service users, and joint decision making and budget setting for preventive services.**

Consultation question 3:

The Government is suggesting three ways in which the National Care Service could be funded in the future:

- ***Partnership***
- ***Insurance***
- ***Comprehensive***

- (a) Which of these options do you prefer, and why?***
- (b) Should local government say how much money people should get in their area, or should national government decide?***

3.1 Funding options

¹⁰ For more information: Mind (2008) *Response to CSCI review of FACS eligibility criteria for social care services*

Mind is disappointed that the Green Paper rules out the option of a fully tax-funded system at this early stage of consultation. 70 per cent of respondents to our survey on 'The Case for Change' felt that a social care system should be free at the point of delivery and funded by general taxation. We believe there are two reasons for such strength of feeling. First, for people experiencing mental distress a system where certain services must be paid for (because they fall under "social care") while others are free (because they are "health" services) is arbitrary and unfair. Secondly, people with mental health problems, at the same time as making higher demands for services which may cost them financially, are more likely than other groups in society to face serious financial disadvantage.

Mind believes the general taxation model should still be considered in any further discussion of funding options, for these reasons. Additionally, none of the three options outlined in the Green Paper provides an obvious solution. The three models seem to be geared towards older people and their likely needs. The Government states that it will 'look at' a system of free care for adults under 65 as part of the Comprehensive model, but there is no other mention of how the different models would impact upon adults of working age who have care and support needs – either in terms of access to services or possible financial contributions. In particular, while there has been some modelling in respect of adults who are born with a disability, we are not aware of any analysis the impact of different models on people who develop a condition during adulthood, such as a mental health condition. We have written to Phil Hope, Care Services Minister, to seek clarification on how the Government proposes the funding models will work for people with mental health problems and await his response with anticipation.

Mind's recommendations:

- (19) The Government should reconsider both the economic and equity benefits of a funding option including general taxation or national insurance contributions.**
- (20) There needs to be far more detailed modelling on how the three funding options would work in practice for adults of all ages with different needs, followed by further consultation on these options.**

It is difficult to offer comment on the three models set out in the Green Paper, given the lack of detail around how they might impact on people with mental health problems. However, Mind would highlight the following general concerns which the Government should take into account when revising their proposals.

3.1.1 Economic disadvantage

Mind's experience and recent research highlights the extent to which people with mental health problems are more likely than other groups to face serious financial disadvantage.¹¹ People experiencing mental distress often live on lower than average incomes: over 75 per cent are reliant on welfare benefits¹² and unemployment rates are as high as 76 per cent.¹³ Mental health problems can act as a pathway to debt, and debt can lead to mental distress. It is therefore crucial that any future funding system does not further disadvantage people with mental health problems, nor create a disincentive to access services for this group, nor penalise those who are least able to contribute to the cost of care.

¹¹ Mind (2008) *In the red: debt and mental health*

¹² Office for National Statistics (2002), Labour Force Survey, LFS, London

¹³ Office for National Statistics (2003), Labour Force Survey, LFS, London

We are concerned about the implications of a Partnership model which might require people of working age to contribute towards their care and support costs. Although the Green Paper states those on the lowest incomes would still get their care free, the impact of such a model on individuals will depend entirely on where thresholds for means-testing are set, about which the Green Paper is silent. For many people living with mental health problems, learning difficulties or physical disabilities, care and support may be needed for the same reason that they are unable to work and save money. People with fluctuating mental health conditions may work sporadically during their lifetime, and therefore reach the threshold for contributing towards their care costs during some periods and not others.

Mind's interviews with service users illustrate the difficulty faced by many people with mental distress in meeting the basic costs of day-to-day living – bills, food, rent, transport and so on – and the potential impact contributing to their care would therefore have; either forcing them to cut back on essentials like food and petrol, or to give up the support they receive.

Case studies: financial hardship

Joan¹⁴, who has schizoaffective disorder, currently has home visits from a support worker for two hours per week, who helps her to keep on top of things in her flat and accompanies her shopping or to hospital appointments. She currently receives this care free. Joan receives Incapacity Benefit, Disability Living Allowance and a small occupational pension. Joan says that if she had to contribute towards her care she would probably have to cut down on food and visiting friends, as she wouldn't want to lose the home support which helps keep her well and out of hospital.

"The support worker organisation, they were quoting £17 an hour well for two hours that would be over £30 a week and there's no way I could afford that."

John has affective bipolar disorder and sees his care coordinator, who is a social worker, once a week. If he had to contribute towards his care he believes he would have to go without food, so he simply would not be able to access the support.

"What my local authority are talking about is £33 an hour to see my care coordinator, 2 hours a week, that's £66, that's half of one benefit gone."

Sarah has bipolar disorder and currently receives free social care. She sees a social worker once a month and attends 'work wise' vocational training twice a week. She receives Employment Support Allowance and Disability Living Allowance. Her husband is working, so Sarah believes that if thresholds were calculated on a household basis, they would have to contribute to her care, which would have a big impact on their finances.

"Our household budget's fairly tight because I'm not working. I think we would have to go out less, use the car less. I think that's the only thing that's got a bit of give on it really and then that would mean that we wouldn't see our children quite so much because they're up in Norfolk [...] you can only cut things so much [...] see my ESA

¹⁴ Names have been changed to preserve anonymity.

pays for my debts and then my DLA pays for going out, for the petrol in the car really [so I can go to 'workwise']”

Mind’s recommendation:

(21) The Government must ensure that any future funding system does not have a further negative impact on people with mental distress, who are already a disadvantaged group in society.

3.1.2 Insurance-based models

“If a particular illness runs in one’s family (dementia, schizophrenia, depression etc.) insurance companies might consider you more at risk and raise the cost of your policy or not cover certain conditions. Since conditions such as schizophrenia generally start in the early 20s, one would have to start putting money aside whilst a teenager.”

“Many insurance schemes in everyday life and the financial industry tend to exclude people with mental health problems.”

People with mental health problems are rarely born with a condition, but may develop one at any given time in their life. Moreover, people with fluctuating conditions such as bipolar disorder or schizophrenia may work for some periods of their lives – and in theory therefore be able to contribute towards a savings scheme – but at other times be on a very low income and require free care. The two models based on either state or private insurance are therefore inappropriate for people with mental distress, who are unable to predict their condition in the same way as someone might anticipate a deterioration in health due to old age, and can not save accordingly. Furthermore, as outlined above, many people with mental distress are on low incomes and may never be able to save.

The funding models outlined only serve the needs of older people and there is insufficient detail on how they would work for disabled people under 65. Mind would welcome reassurance from the Government that, if any funding model based on insurance were adopted, there would be a system of care which is free at the point of delivery alongside this, for adults of working age with care and support needs. The Government has said that the ‘majority’ of disabled people would still get their care for free, so we would like further clarification on what this means in terms of numbers – and what would happen to those who are not covered. Furthermore, in light of the significant barriers to accessing social care faced by people with mental health problems, further modelling needs to take into account thresholds for need and how the funding system can enable the principle of prevention to become a reality in service provision. Mind would be keen to assist the Department of Health with this work and would welcome a meeting, before the White Paper is published, to discuss these issues in greater depth.

Mind strongly rejects any proposals to adopt a model based on private insurance. Aside from the issue of people being unable to afford insurance payments, we have serious concerns that people with mental health problems could be doubly penalised for their needs by discriminatory insurance policies that categorise them as “high-risk”. Despite the existence of the Disability Discrimination Act, there are many

instances where insurers can still justify discrimination on the basis of a mental health problem.¹⁵

Mind's recommendations:

(22) The Government should clarify, with detailed modelling, how a free system for people under 65 would work alongside the Comprehensive model.

(23) A funding system based on private insurance must not be adopted, as such an option would discriminate against people with mental health problems, if they were expected to contribute.

3.1.3 Disability related benefits

Mind is concerned by the Green Paper's suggestion that Attendance Allowance (AA) and 'other disability related benefits' might be pooled with general social care funding in the future. Since the Green Paper was published Mind has been contacted by a huge number of people who are concerned about this proposal, because they place a high value on the independence and personal flexibility afforded by benefits such as the Disability Living Allowance (DLA) and AA. They are an important part of the support offered to people with mental health problems and provide help with the additional costs of living with a disability, which are distinct from care costs.

In our survey, most respondents who received DLA/AA used it for social activities to reduce isolation, transport costs, and to help with basic living costs (bills and food). Other uses ranged from internet and telephone costs for maintaining social contact during distressing periods, to buying special food to cope with eating problems.

We warmly welcome the announcement by the Secretary of State that the Government has ruled out abolishing DLA for under 65s. However, we remain concerned that DLA for over 65s and AA are still on the table. We oppose any moves to end such benefits and are particularly concerned about the implications for people receiving DLA when they reach 65 – it would be unacceptable for their benefit payment suddenly to end at this age. There are also implications for age inequality; for example, if someone developed depression aged 66 it is unfair that they would not be eligible for DLA, whilst they would have received the benefit had they become ill two years previously, at the age of 64.

Mind's recommendation:

(24) Disability Living Allowance for over 65s, as well as under 65s, and Attendance Allowance for all must be retained.

3.2 A national or a local system

Mind would support a national system of decision-making, where the amount of money spent on an individual is linked to the national assessment process. Otherwise the welcome move towards national eligibility and entitlement will be diluted, as local authorities will still determine funding levels, enabling the postcode lottery to continue. If people continue to be granted different levels of service depending on where they live, the principles of a National Care Service will be undermined, with significant implications for health inequalities across the country, particularly given the pressures to cut services due to the recession.

¹⁵ Mind (2005) *Insurance cover for people who have mental health problems*

However, there needs to be further clarification about how the ‘fully national’ and ‘part-national, part-local’ models will differ in terms of funding, for example in terms of the balance between national taxation and revenue raised from council tax.

Mind’s recommendation:

(25) The Government should carry out further modelling of how a national system, where the national assessment process is linked to the amount of funding allocated to an individual, would work in practice, particularly around the tension between locally and nationally raised taxation.

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Appendix One: Methodology and profile of respondents

In Autumn 2008 Mind published a questionnaire on its website, and distributed it to Mind's networks of local Mind associations, of service users (Mind Link), and campaigners (Mind in Action). We received 101 responses in total. In addition, we held three workshops with service users at Mind Link road shows in different locations around the country (Brighton, Newport, and Exeter). We also received individual responses from readers of the Mind Link magazine, where we published an article about the care and support debate.

Among respondents to our questionnaire, 61 per cent had used social care services in the last two years. 98 per cent had experienced mental distress and/or used mental health services in the last two years. 80 per cent of respondents using social care (35 out of 44) did not have to pay a charge. This included both statutory and voluntary sector services. Seven per cent (three) paid a means-tested charge to the council, and five per cent (two) bought their care services privately.

In September 2009 Mind conducted a number of interviews to delve into some of the issues raised by the Green Paper, and particularly to map how the funding models might affect individuals. All interviewees had experience of mental distress and were using social care services.

Appendix Two: In-demand services

We asked people which additional services and types of support would help them to live more independently. As the table shows, practical assistance with day-to-day living (shopping, finances, benefits advice, housing), support with engaging in community activities, and advocacy were the most in-demand.

Service	Number who said this service would help them to live more independently
support with managing my money, paying bills etc	34
support to engage in community activity	31
support to do the shopping	23
advocacy	22
benefits advice	21
housing support	19
help around the home	17
meals on wheels, or help preparing a meal	12
employment support	10
personal care support	9
support with parenting	5
residential care (such as a nursing home)	2