

## Submission to the Barker Commission

### Introduction: MND and future care challenges

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. MND care is highly demanding and multidisciplinary in character: between 15 and 20 health and social care professionals may be involved in a person's care, and care must be not only timely but often anticipatory in order to meet the person's changing needs as the disease progresses. It is as stiff a challenge as the health and care systems ever face.
- iv. The nature of MND care and treatment has changed in recent decades, and is likely to change more radically in the future. While there is only one drug that is known to slow MND, more widespread use has been made of interventions such as gastrostomy and non-invasive ventilation. These interventions represent modest but welcome progress in improving care for people with MND, but also pose multiple challenges: there still needs to be greater consistency in making them available; funding for them can sometimes be hard to access; and health and social care professionals can often be un-trained in how to use them, in some cases refusing point-blank to assist the person with MND. MND care in this respect is only going to become more complex, and as medicine becomes more stratified and targeted at specific genetic mutations, care demands may be magnified by the development of new drugs leading to some people with MND surviving substantially longer than at present and requiring support over a longer period (although no such targeted drug has yet been discovered and proven to work). This is the context in which we address the Commission's questions about the future health and care settlement.

**1. Do you agree with our conclusion that a new settlement in health and social care is needed?**

- i. We are struck that there is remarkable policy consensus around the transformation that needs to occur in the delivery of health and care services in order to respond to demographic and technological changes. Services must be more integrated, be structured to respond to chronic disease and not just acute disease, provide greater measures of prevention, and be less reliant on generalist acute centres, with health services instead focused more in either the community or specialised centres as appropriate. The remaining debates appear to be over how to make these changes, and the balances to be struck in achieving them (for instance, the future role of district general hospitals).
- ii. MND provides a strong case study of the benefits that such a transformation can bring: supporting a person with MND to live independently for as long as possible produces better outcomes for them, while failure to do so results in costly hospital admissions and emergency interventions to remedy the consequences of poor care.
- iii. Identifying the future financial settlement for health and care is therefore made more complicated by the pressing need to change the nature of those services. Ongoing political fixation on the structures by which they are provided adds further complexity. Do we need to change the level of resource available for these services, and do we need to change how those resources are drawn together? On balance, our view is that the answer to both questions is yes: in respect of social care in particular, we believe that new funding must be brought into the system, and that any attempt to argue that the current settlement is adequate is unsupported. The complex and problematic nature of social care funding in particular means that this will almost certainly require new mechanisms to draw funding into the system, and a new agreement across society over how this is to be done.
- iv. We would also add that the boundaries of the health and social care system are not as clear-cut, in respect of funding, as they might first appear. The Commission's interim report addresses possible overlaps with welfare benefits. Other aspects of public services might be added to this list: legal aid is one, as this may be necessary in order to enable people to challenge social care funding decisions (and we are currently seeing cuts to one hobbling people's ability to challenge cuts to the other); funding for the police service is another, as the consequences of failures in mental health services can often be picked up by the police. There are no doubt other examples, and we will return to this issue in response to later questions.

**2. If so, do you support our proposition for a single, ring-fenced budget for health and social care which is singly commissioned, and within which entitlements to health and social care are more closely aligned?**

- i. We agree that health and care services should be funded from a single ring-fenced budget. We question the assumptions underpinning the recommendation that this should be a budget from which services are "commissioned".

- ii. The need for a single pool of funding across health and social care can be seen from the current tendency of the system to engage in cost-shunting: it is entirely rational, when both health and social care services are finding resources tight, that they should seek to push up-front costs to another agency. At present, social care funding is in crisis while NHS funding is merely seriously stretched, so it appears to be more common for social care to push responsibility to the NHS, for instance when agreeing plans for a person's discharge from hospital. It is unforgivably distressing for a person with MND and their family to see the establishment of new care arrangements delayed while different services wrangle over money, and this must end.
- iii. That said, costs are not merely shunted between the NHS and social services; they can also be shunted within either service. The divide between specialised and general commissioning is a boundary across which costs can be shunted; costs can also be shunted between different tertiary centres, or even within hospitals. This can never be entirely eliminated: any provision of any service will involve some degree of departmentalisation in order to make the service function. It becomes a particular problem when responsibilities are unclear, allowing different bodies to make a case for someone else acting and not them, or when money is tight, creating an incentive to do so.
- iv. Inadequate funding can also give rise to other problematic behaviour within the system, as has been evident in social care for many years: waiting times for assessments are long; there is pressure on social workers to close cases, so that anyone with a change in need goes to the back of the queue for a new assessment (although similar pressure also applies elsewhere, for instance occupational therapists and physical therapists increasingly appear to be under pressure to close cases, for instance if a set number of sessions has been completed, and require a re-referral); panels reject proposed care packages on spurious grounds such as spelling errors or an insistence on trying to obtain NHS continuing healthcare, even though it may be clearly inappropriate. All of these behaviours bring the benefit of saving a few days' worth or weeks' worth of cash, but all of them compromise the care provided to the individual and increase the chances of inadequate prevention requiring a more substantial intervention at a later stage – at which point the cost will probably fall to the NHS. So we believe that the chasm between health and social care funding must be eliminated, and that the level of resource available to the system as a whole must be increased.
- v. While we note the recommendation in the interim report that even if there is a single pool of funding it is not appropriate to expect there to be a single organisation to spend it and provide all services, we strongly recommend that the Commission considers more carefully the implications of this, and what might be meant by "commissioning" in this context.
- vi. The context to this is the substantial shift, over the last three decades or so, to the delivery of public services in a manner in line with the so-called 'new public management', involving 'markets, managers and measurement' and an ostensible focus on securing value for taxpayers' money. Public services are now typically commissioned by government (local or central) using commercial contracts; in other words government has become a purchaser and commissioner of services,

not a provider. On the ground, it might be noted, the services and the people delivering them are on a basic level largely the same: hospital wards still have nurses, buses still have drivers, bins are still collected by (mostly) men in lorries, and so on.

- vii. These ideas are now rather old (older than the post-war model of monolithic state provision was when the 'new public management' gained currency), and represent the status quo and received wisdom of our times. Their impact should be examined across all areas of public policy, not just health and care. Debate around their impact currently appears unfocused, however. While there are abundant media stories of specific contracts for this or that service proving poor value for money, there is no consensus about what conclusions should be drawn from this. Some argue that the problem is consistently poor performance by government in procuring and managing commercial contracts, but that the underlying model is sound. Others suggest that the commissioning model itself may not in fact be appropriate in many circumstances, although this view appears not to be strong within the political mainstream.
- viii. In health and care however, these issues have been considered. There is currently much debate around the performance of commissioners in the NHS, and divides such as that between specialised and general commissioning. It can be seen that while commissioners will in theory identify need and purchase services to meet it, they will only ever do so in areas for which they have specific budgetary responsibility. While there may be higher tiers of responsibility, whose role it is to identify areas of unmet need for instance, these may not have the ability to direct commissioners to address them (for instance, clinical commission groups are autonomous and cannot be directed to NHS England to commission a particular set of services, no matter what evidence might exist of unmet need; local authorities enjoy a similar measure of autonomy in respect of many services).
- ix. The recent reforms of the NHS in England represent the most thoroughgoing implementation of the commissioning model yet seen in the NHS. Stephen Dorrell MP, chair of the House of Commons Health Select Committee and a former Secretary of State for Health, has described them as, "probably the last chance to get commissioning right."<sup>1</sup> Another former secretary of state, Ken Clarke, has in the past gone as far as to say: "If one day subsequent generations find you cannot make commissioning work, then we have been barking up the wrong tree for the last 20 years."<sup>2</sup> We therefore recommend that the Commission does not make assumptions about the nature of "commissioning" from a single budget, or at least does not leave any such assumptions unspoken.
- x. Indeed, modern alternatives to a commissioning approach can be identified. The purchaser-provider split was abolished in the NHS in Scotland in 2004, and Wales in 2009. In England, there is significant debate around capitated or 'year of care' funding models, or 'integrated provider organisations'; all of these models have the net effect of funding a provider organisation per patient, and making it responsible for all of that person's care, rather than each aspect of care being

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<sup>1</sup> [Financial Times, April 7 2011](#)

<sup>2</sup> [Never Again? The Story of the Health and Social Care Act 2012](#), King's Fund / Institute for Government, 2012

commissioned separately. It is debatable whether commissioning as currently practised has much of a place in any of these models. The same might be said of personal health budgets, which are currently being introduced in the NHS in England, and of the longer-established direct payments for social care. Indeed, even where commissioning currently operates, it might be asked how much power commissioners have in effecting service transformation, relative to the provider organisations – which, after all, contain the clinicians and other healthcare professionals who will provide the actual care and treatment. In short, it is open to question whether commissioning is an effective way of funding health and care provision, and of driving the service transformation that the system is widely agreed to need. It may be that on examination commissioning is found to be the best model; but we advise the Commission to consider the issue and instigate a debate, not merely to assume that the current model must continue.

**3. Should the aim be to achieve more equal support for equal need, regardless of whether that support is currently considered as health or social care?**

and

**4. If your answer is yes to question three, should social care be more closely aligned with health care (that is, making more social care free at the point of use)? Or should health be aligned more closely with social care (that is reducing the extent to which health care is free at the point of use)?**

- i. We are not convinced by the assertion in the interim report that Attendance Allowance, a cash benefit, can be seen straightforwardly as an example of social care. Like its equivalent for people of working age, Personal Independence Payment (and its predecessor, Disability Living Allowance), AA can be used in a variety of ways to meet a variety of needs, and we do not believe that lumping it in with social care does justice to its role in the lives of many people. Rolling it into the social care funding ‘pot’ was mooted by the Dilnot Commission; now, as then, we would not support such a proposal.
- ii. On the wider question of whether and how the funding settlements for health and social care should be more closely aligned, we certainly recommend that the current gross imbalance in the degree to which they are adequately funded should be corrected. At the very least, this is likely to require additional funds to resolve the current crisis on the social care side of the divide (which would still be apparent even if a single budget for the two services were created).
- iii. In terms of paying for this, we felt the Dilnot model for social care offered an attractive solution in the context of that Commission’s frame of reference: it effectively created a model of social insurance with an excess. We note however that as currently being implemented, the excess is ungenerous and few people will benefit. Moving healthcare funding to any model of this sort, which would require payment at the point of use up to the value of the excess, would be politically unviable in England or any other part of the UK. Aligning the two models must therefore involve making social care free, or close to it, at the point of use. This limits the options for bringing new funding into the system, which we consider in response to question five.

**5. Do you think that adequate funding for health and social care requires:**

- a. Increased charges in the NHS? If so, for what?
  - b. Increased charges for social care? If so, for what?
  - c. Cuts to funds from other areas of public spending, re-allocating it to health
  - d. and social care? If so, from what?
  - e. An increase in taxation? If so, which taxes would you favour increasing?
  - f. None of the above? If you answer yes to this, is it because you think that funding for health and social care is adequate, and that extra demands can be met by using existing resources more efficiently? Or is it for some other reason?
  - g. All of the above? If you answer yes to this, and think that elements of all or some of these changes may be needed, which mix would you favour, and to what degree?
- i. Firstly, we believe that there is significant scope for using existing funding more efficiently in respect of neurology services. The National Audit Office's report 'Services for People with Neurological Conditions' found that an increase in NHS spending on neurology had not been matched by an improvement in health outcomes.<sup>3</sup> The factors that led to this failure – low prioritisation of neurology within the NHS, and a lack of national leadership with clear authority and adequate resources to deliver change – persist in the reformed NHS.<sup>4</sup> And as in many other areas of care, there is ample scope to improve both patient outcomes and value for money by improving care early on in the MND pathway, and so avoiding high-cost crisis interventions at later stages – although these require up-front investment that a cash-strapped system will usually be unable to deliver.
- ii. However, while efficiency improvements may be sufficient to deliver more effective healthcare, we do not believe that they would be sufficient to balance out the crisis in social care funding as well: spending on adult social care has been flat or falling in England since 2004-5, and fewer people are receiving state-funded social care now than a decade ago, despite rising demand. Such a reduction in spending by successive governments represents a perverse and inexplicable pattern of decision-making, and a substantial infusion of new funding will be necessary to reverse the damage.
- iii. We do not see it as the role of health charities to make recommendations on the distribution of spending across government, and we will therefore not be making recommendations for how the necessary extra funds should be raised. We note, however, that the option for paying social care charges from a person's estate, as implemented as part of the Dilnot reforms, could potentially be made to apply to both health and social care as part of the creation of a single budget for the two. This would however represent a shift to introducing charges for specific items of NHS care, over and above existing prescription charges (albeit to be paid posthumously). Again, we do not feel this would be politically acceptable in the UK; creating a new levy to be taken from estates specifically for the pooled health and social care fund, rather than as a bill for individual care services used during the person's lifetime, may be more palatable (though even this would be a version

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<sup>3</sup> [National Audit Office](#), 2011

<sup>4</sup> [Going the Distance: national calls to action to drive neurological service improvement in England](#), Neurological Alliance 2014

of the proposal dubbed a 'death tax' ahead of the 2010 general election; it is not certain, however, that making the political case for such a levy would be impossible).

- iv. Finally, we urge the Commission to make recommendations about decision-making within fiscal policy in the UK. The long-standing crisis in social care, and the crisis that many predict will face the NHS within the next year or so, arise from a wider government framework of 'austerity' which has been justified politically on the grounds that it is necessary to effect an urgent reduction in the Government's borrowing in order to restore the wellbeing of the economy. We note that this is at best a highly debatable proposition within mainstream macroeconomics. The spending cuts and constraint that have been implemented in aid of this policy have had a serious impact on the delivery of health and care services (both directly and indirectly – for instance, benefit cuts implemented as part of the same agenda appear to be generating additional costs for the NHS). For health and care services to be sustainable and of a high quality, their funding must be not only sufficient but stable; this requires fiscal policy to be formulated responsibly, and without experimentation in macroeconomic policy that is not clearly needed or justified.

## **6. Further areas for consideration**

- i. The interim report neglects to consider the voluntary sector as a source of health and care funding. While some charities are commissioned as providers, others fund services and effectively mask need. Very often these are long-standing arrangements, originally instituted because statutory services showed no sign of being able or willing to meet this need themselves. However, this funding must be quantified and the correct way to continue it considered in any formulation of a new settlement for health and care.
- ii. The MND Association currently funds specialist nurses and co-ordinators to run specialist MND clinics or networks (care centres) in 17 locations in England, and one each in Wales and Northern Ireland. In total this amounts to a subsidy to the NHS of approximately £1million per annum. We also fund a wheelchair service in Oxford (which we are extending to London and Leeds, this time with DH funding), and regularly loan communication aids to people with MND. Currently we are also funding some assessments and items of communication equipment owing to a collapse of NHS provision across much of England following the changes to specialised commissioning arrangements in October 2013. All of this provision is in spite of these responsibilities resting unambiguously with the NHS – the reforms to specialised commissioning have in some cases provided new clarity about these obligations. We believe that numerous other patient charities fund services in a similar way, often by agreement with NHS provider organisations. Commissioners often remain oblivious to the presence of charitable funding, and assume that because an activity is happening in a service they commission, it is paid for out of the funding they provide – this is not always true.
- iii. We understand the Commission's reasons for not wishing to set out a prescriptive offer of what the NHS and social care will and will not provide, and on balance agree with it. We recommend, however, that it offers advice on what, in principle, the role of statutory services should be vis-a-vis the role of the voluntary sector.

No new settlement that sets out the balance between the payments made on a collective basis (via tax or insurance) and payments made for services at the point of use can be complete without also considering payments made via charitable donations, which represent a third source of funding for health and care services.

- iv. We also recommend that the Commission sets out where spending on research in the NHS and social services sits in the new settlement, and what our expectations should be of each organisation in respect of research. The recent NHS reforms placed new duties on the NHS in respect of research, which we welcome. We hope that the debate instituted by the Commission's report will foster a greater expectation of research as core NHS and care activity.

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