mnda
motor neurone disease
association
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Guidance in relation to Part 9 of the Act on Co-operation and Partnership

Consultation Response Form

31 July 2015

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Responses should be returned by **31 July 2015** to:

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Introduction

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, approximately 250 of them in Wales. 30% of people with the disease die within 12 months of diagnosis. There is no cure.

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.

Summary of response

The MND Association welcomes the principle of joining up social care and health in order to ensure that the population's needs are effectively met. We welcome the priority focus on older people with complex needs and long-term conditions and on carers, both of which will enable people with MND and their families and friends to receive the support they need.

However, there are a number of improvements that could be made to the regulations and statutory guidance that would increase the effectiveness of this system in helping people with MND to achieve well-being outcomes. Our recommendations are as follows:

- Include a housing lead on the regional partnership boards to ensure that housing and adaptation needs are fully considered as a central part of a person's care and support
- Add more explicit guidance on co-opting specialists in different conditions such as MND where there is a need
- Ensure a level of accountability for third sector and care provider representatives on the regional partnership boards
- Expand the scope for pooled funds and make explicit the benefits and options for establishing pooled funds outwith care home services and integrated family support functions.
- Include neurological conditions as a priority focus
- As far as possible, ensure that regional partnership boards are coterminus with other structures and systems.

Cooperation & Partnership

1. Do you agree with the proposed membership of the regional partnership boards?

Agree	☐	Tend to agree	☐ x	Tend to disagree	☐	Disagree	☐

Please provide additional information as necessary to support your response – suggesting any changes or additions to the proposed membership.

The MND Association welcomes the range of individuals involved in regional partnership boards, including representatives from the voluntary and independent sectors, as well as a person representing public and patient voice.

We strongly recommend including a local housing lead on the partnership boards, in addition to the existing list, especially given the inclusion of certain housing functions in Schedule 1 (Regulation 8) of the regulations determining the scope of partnership arrangements. Ensuring that a person is able to live in a safe, accessible and adaptable home is crucial to managing a person's social care needs, and housing must be treated as a central part of the integrated health and social care system. Successful home adaptations, for instance, enable a person with MND to remain in their own home and receive care in that setting, at a considerably reduced cost compared to a residential setting.

We appreciate the inclusion in the statutory guidance which states that Regional Partnership Boards may co-opt other persons to the board as appropriate. We would encourage the Government to explicitly state that these other persons might include specialists in certain conditions. MND is a complex illness and people with MND need a range of specialist services; the presence of a specialist neurologist, for instance, would help the Board to fully capture these complex needs.

We also urge the Government to consider mechanisms for ensuring that the third sector and the care provider representatives are appointed through a fair and transparent system. The representatives must be able to bring the views of a range of organisations working with a range of people to the boards for consideration, and there should be measures in place to hold them to account on this front.

2. Do you agree with the proposals for pooled funds?

Agree	☐	Tend to agree	☐	Tend to disagree	x ☐	Disagree	☐

Please specify if there are any other areas that should be considered, highlighting the one key priority area.

The MND Association welcomes the inclusion of pooled funds for care home accommodation functions in the regulations. It is important that these pooled funds consider the need for specialist staff, such as specialist nurses, for people with MND, to ensure an adequate level of support in the care home setting.

We believe that the proposals are too narrow in their scope. Pooled budgets for other aspects of social care support in home settings, including funds for end of life care, respite care and housing adaptations, recognise the cost benefits to the health service of the social care system. The Government should make explicit in statutory guidance and regulations the importance of pooled funds in areas beyond care homes and Integrated Family Support Services.

3. Do you agree with the priority areas identified for regional partnership boards:

- Older people with complex needs and long term conditions.
- Integrated Family Support Services.
- Learning disabilities.
- Children with complex needs due to disability or illness.
- Carers.

Agree	☐	Tend to agree	x ☐	Tend to disagree	☐	Disagree	☐

Please specify if there are any other areas that should be considered, highlighting the one key priority area.

We welcome the inclusion of carers on the list of priority areas for regional partnership boards. Families and friends of people with MND provide considerable levels of unpaid care, and their own support needs must be recognised. We also welcome the inclusion of older people with complex needs and long term conditions; roughly two thirds of people with MND are aged over 65, so it is important that this group with complex needs is represented.

The MND Association believes that people with neurological conditions, including MND, should be included on this list. 500,000 people in Wales are thought to be affected by a neurological condition and 100,000 will have a long-term condition.[1] People with a neurological condition such as MND will have complex and progressive social care needs, as well as clinical health needs, and care services will need to be responsive and well-planned in order to make sure that people get the help that they need in a setting of their choice.

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[1] Welsh Government, *Neurological Conditions Plan*, 2014

4. Do you agree with the proposals in relation to integrated family support services?

Agree	☐	Tend to agree	☐	Tend to disagree	☐	Disagree	☐

Please explain why.

This section is beyond the scope of the work of the MND Association.

5. Do you agree the proposals will lead to improved outcomes for people and make more effective use of resources?

Agree	☐	Tend to agree	☐	Tend to disagree	☐	Disagree	☐

Please set out where further action should be taken.

These proposals have the potential to increase partnership working, joint responses and joint commissioning in some areas, which may lead to improved support for some people with MND. Responding proactively to the recommendations that we have made above and below will both improve outcomes further for people with MND and encourage better use of resources. In particular, we urge the Government to consider the following recommendations:

- Include a housing lead on the regional partnership boards to ensure that housing and adaptation needs are fully considered as a central part of a person's care and support
- Add more explicit guidance on co-opting specialists in different conditions such as MND where there is a need
- Ensure a level of accountability for third sector and care provider representatives on the regional partnership boards
- Expand the scope for pooled funds
- Include neurological conditions as a priority focus
- As far as possible, ensure that regional partnership boards are co-terminus with other structures and systems.

Other

The Welsh Government is interested in understanding whether the proposals in this consultation document regarding part 9 will have an impact on groups with protected characteristics. Protected characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation.

6. Do you think that the proposals in this consultation will have any positive impacts on groups with protected characteristics? If so, which

and why/why not?

As described above, the proposals have the potential to improve systems for people with disabilities such as MND, particularly if the recommendations above are followed. There are many different professionals involved in the lives of people with MND; ensuring these professionals are able to communicate and work together effectively is crucial to making sure people with MND are able to navigate the system effectively and receive the range of support they need.

7. Do you think that the proposals in this consultation will have any negative impacts on groups with protected characteristics? If so, which and why/why not?

We do not believe so.

8. Re-balancing the care and support system to deliver the new legal framework will require reprioritisation of resources. What are the key actions that need to be taken to achieve this?

The system will require initial funding from health and social care partners to establish regional partnership boards and arrangements. The social care system itself will need ongoing, sustainable funding in order to both provide the care and support that people need to achieve well-being outcomes, and to realise potential cost savings to the health system. This includes funding to fill gaps in local advocacy services in order to meet statutory requirements, and funding for specialist services to ensure that people with MND have real choice. Ultimately the funding of social care saves the whole system money, and any reprioritisation of resources must reflect this. Joint funding arrangements recognise this to some extent in some areas, and further joint funding of social care services will deliver further savings to health and other services.

9. We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to tell us about them.

We have some reservations about the geography of the Regional Partnership Boards. The Mid and West Regional Board, for instance, covers a large geographical area, as well as two partnership arrangements, two population assessment areas and two separate Health Boards. Proposals for new local authority boundaries also do not match up to the Regional Partnership Boards in a number of areas although we appreciate that these plans are still under discussion. Every effort should be made to make sure different structures are coterminous in order to ensure that services can work

together in the best way possible, and that the system is easily navigable for those who use it.

Responses to consultations may be made public – on the internet or in a report. If you would prefer your response to be kept confidential, please enter YES in the box.	