



**Response of the Neurological Alliance to the Department of Health's
'Caring for our future: shared ambitions for care and support' engagement
exercise**

December 2011

About the Neurological Alliance

The Neurological Alliance is the collective voice of 80 brain and spine charities, representing the 8 million children and adults in England with a neurological condition. The Alliance campaigns for access to high-quality, joined-up services and good information for every person diagnosed with a neurological condition, from their first symptoms, throughout their life. More information is available at www.neural.org.uk

Overview

The Neurological Alliance welcomes the opportunity to input to this engagement exercise.

There can be no doubt of the need for reform of the social care system in England; the complexity, inequity of provision and chronic lack of funding under the current arrangements requires that the Government urgently establishes a system in which these issues are resolved.

Access to integrated health and social care services is paramount to enabling individuals with neurological conditions to achieve the highest quality of life possible. However, for the vast majority of people affected by neurological condition, joined up, high quality care remains an aspiration.

Progressing of the recommendations of the Law Commission and development of the Dilnot Commission's recommended funding mechanism collectively represent a crucial opportunity to devise an improved and fairer social care system.

Our key priorities for social care reform are that the emergent system:

- is **adequately resourced** to ensure that unmet need is addressed
- guarantees that service users and their carers have access to **equitable, high quality care and support services**
- recognises the vital importance of **integration** within and between health and social care and incentivises **multidisciplinary working**
- **champions personalisation**, the interpretation of which goes beyond personal budgets and direct payment
- makes available it the appropriate **information, advice and support** to enable people with long term care and support needs to choose how and where care and support is delivered
- **invests in prevention and early intervention** to enable people with care and support needs to maximize their quality of life

Improving quality and developing the workforce

High quality must underpin the provision of care and support across health and social care. Regulators, commissioners, providers and care workers all have a key role to play in maintaining and improving care quality. However, the Government retains ultimate responsibility for driving this process, either through financial incentives or centrally administered regulation.

Neurological conditions, particularly those that are rare, are generally little understood by members of the health and social care workforce. Given the often regular interaction between people with neurological condition and social care services, the typically poor training of social care professionals gives cause for particular concern.

We support calls for a national approach to the development of the social care workforce and a workforce strategy that attracts the necessary training funding.

Increased personalisation and choice

For people living with long term neurological conditions, personalisation represents the chance to exercise choice over the services that meet their care and support needs to ensure that these are tailored to suit them.

We welcome the intention to extend the availability of personal budgets recognise the benefits that they can offer people with long term care and support needs.

For those individuals who choose to receive a personal budget, the provision of information and advice, advocacy and brokerage support is absolutely crucial; without this support, there exists a real risk that the benefits of a personal budget will be undermined by ill-informed decision making.

The Neurological Alliance stresses, however, that personal budgets and direct payments will not be right for all people with long term care and support needs. Personalisation must be understood much more broadly to encompass alternative arrangements; for example, the delivery of a care plan, devised in consultation with a service user, by a multidisciplinary team.

Ensuring services are better integrated around people's needs

Most neurological conditions require multidisciplinary care; as such, integration within and between health and social care is absolutely essential. However, the fragmented health and social care arrangements currently in place mean that those with long term conditions are routinely required to navigate a complex environment of service providers and professionals in order to access the care and support they are entitled to.

The lack of coordinated care is a particular problem for individuals with fluctuating or degenerative neurological conditions, resulting in unnecessary hospital admissions at a considerable cost to the NHS. Conversely, where services are successfully joined up, unplanned acute admissions can be minimized, home care made easier and quality of life maximised.

The Neurological Alliance strongly supports the new and explicit commitment to integration and advocates the need for a multidisciplinary approach across health and social care for people with neurological conditions.

Supporting greater prevention and early intervention

Prevention and early intervention are fundamentally important for people living with neurological conditions, helping individuals to retain independence for the maximum period of time and, where relevant, remain in employment and plan for relapses. Prevention and early intervention also reduce costs that more complex interventions necessary in their absence can incur.

We emphasise the central importance of investment in prevention and early intervention and stress the need for the social care white paper to be a cross-governmental initiative that ensures prevention services are coordinated and comprehensive.

It is important to recognise that not all neurological conditions are preventable and we stress the importance of guarding against a culture of blame aimed at individuals with care and support needs arising from unavoidable conditions.

Creating a more diverse and responsive care market

In respect of creating a more diverse and responsive care market, we would highlight the substantial contribution that the voluntary sector has to make. Within neurology, for example, our charity members and national network of Regional Neurological Alliance have a wealth of experience and can use their significant capacity to both support and provide integrated health and social care service for people with neurological conditions.

The role of the financial services sector in supporting users, carers and their families

Given the complex and degenerative nature of many neurological conditions, the Neurological Alliance is concerned that emergent insurance schemes for social care costs may not cover the potentially high costs associated with such conditions. It is vital that people with neurological conditions can feel confident in any new product in which they invest

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