



Sue Ryder's response to the Department of Health's consultation on the Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies – draft guidance.

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1. About Sue Ryder

Sue Ryder is a charitable provider of health and social care services across the UK. We care for people with long term or complex conditions and disabilities providing specialist palliative and neurological care. We operate in a range of environments with community and home-based care delivery alongside our hospices and neurological care centres.

We are funded through charitable donations, contracts with PCTs and local authorities and revenue from our network of more than 400 shops across the UK.

2. Overview

We welcome this guidance along with the new duties on health and care commissioners and health and wellbeing boards in relation to Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWS). We believe the JSNA and the JHWS could be the key levers to improving strategic health and care commissioning and improving outcomes for those with complex needs and disabilities.

However, the JHWS and the commissioning plans on which they should be based will only be as robust as the evidence collected in the JSNA. We believe it is important that this guidance clearly sets out the content of what should be collected in the JSNA to ensure it is as robust, inclusive and representative as possible. This needs to be done by expanding the core data set and improving engagement with voluntary sector providers.

3. Developing the JSNA

We welcome the white paper on care and support and the duties in the draft care and support bill on local authorities to promote a diverse, sustainable and high quality market of care and support services. As commissioning moves away from block contracting by local authorities towards more individual control over the purchasing process, a varied market will be crucial to ensuring people can purchase a choice of services.

We believe market facilitation is crucial to delivering personalisation. Last year's Demos report, *Tailor Made*, sponsored by Sue Ryder, revealed that individuals with the most complex needs see their lives in broad outcomes and aspirations including maintaining independence, spending time with family and remaining engaged with their community, none of which can be achieved by health or care alone.¹ In order to meet these outcomes multi service integration is required. Personal budgets and the purchasing power of direct payments will only help to deliver personalisation if there is a range of personalised services from which to choose from.

Many of the people Sue Ryder provides care for live with progressive neurological conditions such as Multiple Sclerosis, Huntington's disease or Parkinson's disease. These individuals will live in the care system for many years. Evidence collected for Sue Ryder indicates that these individuals benefit from services that address their specific needs resulting from their condition to help them to achieve their desired broad outcomes. If data is collected about individuals living with specific conditions such as MS and HD for example then providers and commissioners are able to assess what services would best meet the needs of the local population. In addition, individuals would be able to work together to co-produce services with providers to ensure that they have the economies of scale to provide a flexible service.

As such, the development of a market facilitation strategy is directly linked back to having a reliable data source, which we believe should be the JSNA. This is why we believe this guidance should be used to inform local authorities along with the Developing Care Markets for Quality and Choice Programme from the Institute of Public Care and the development of market position statements. Both strategies will rely on the evidence of the needs and assets of the community.

Sue Ryder recently ran an FOI request to local authorities in England asking about the specific design and delivery of services they offer for individuals with complex neurological conditions. Responses were received from 131 local authorities. Only 5% of the local authorities surveyed were able to provide detailed data on the number of individuals with neurological conditions that they provided care services for. 72% of the authorities indicated that they do not

¹ Wood, Claudia, *Tailor Made*, Demos (2011) p.74.

collect detailed data categorising specific neurological conditions. 79% of local authorities indicated that they do not have a specific commissioning strategy for services for people with neurological conditions.²

The results, particularly the lack of data available to identify those living with neurological conditions in local communities is concerning. It makes it almost impossible for local authorities to know the range and numbers of those living with neurological conditions in their area. As a result it is likely that many of these individuals are not receiving the best services for their needs. We believe the information in the initial needs assessment is crucial in determining the shape of future services.

This guidance needs to go further in providing health and wellbeing boards more support in relation to the content of the JSNA and JHWS. Unless the data set is expanded and the JSNA core dataset revised JHWS and market position statements will not be robust enough, and the market won't appropriately meet the needs of those living within it, particularly in the case of those living with neurological conditions.

The white paper on care and support outlines a new asset based approach to social care. In order for local authorities to embed this approach within JHWS the guidance must support them on ways to involve the public and community groups in mapping the whole range of assets available.

We are pleased the guidance stresses the need for transparency and accountability of the JSNA and JHWS. Health and wellbeing boards must be accountable to the public but also to providers.

4. Engaging with the voluntary sector

Encouraging health and wellbeing boards to consider inclusive ways to involve people from different parts of the community will help them to encompass the broader remit of the JSNA. The guidance needs to have a stronger message on local authority engagement with the voluntary sector.

Engaging with the voluntary sector and providers is important because they can play a key role in identifying and supplying the numbers of those from harder to reach groups including those with complex needs and disabilities living in the community. They can offer service user advocacy and representation, knowledge of the community's needs and services and provide the expertise on the specialist services that are needed to improve individual outcomes.

² This data will be released on 24 October 2012 in Sue Ryder's research report into commissioning services for people with neurological conditions and complex needs. For a copy of the report please contact the Sue Ryder policy team, details above.

We would recommend that the guidance encourages the routine engagement with providers and spread of best practice of the engagement process.

5. Interpretation

We are concerned that the guidance, beyond the statutory duties, is too open to local interpretation. The implementation of much of the guidance outlined will depend on local leadership, innovation and buy in from local authority partners. We are concerned that there is too much scope for variation between authorities and this may result in a two tier system, which may adversely contribute to the postcode lottery of care.

The guidance states that health and wellbeing boards will encourage integration. Without an effective integration framework we are unsure how this will be implemented in practice. This will depend more on the strength of local leadership and existing relationships. Therefore the guidance must promote the spread of innovative best practice.

6. Conclusion

Ideally all NHS and social care commissioners will use the opportunity of the JSNA and JHWS guidance to work together to shape integrated services to meet the needs of their local population. We are concerned as we have outlined above that the commissioning plans will only be as strong as the data that they are based on. The JSNA core dataset must be expanded beyond the existing indicators, and the guidance must reflect this. In addition, engagement with the voluntary sector and providers must be more prominently promoted and encouraged.