Health and Wellbeing Board Strategy – Consultation Feedback

"Rise up with me against the organisation of misery"[1], Pablo Neruda

This important call from the Marmot review resonates with us all to deliver better intervention and prevention across society. The response of the Health and Wellbeing Board in the 'Rotherham Borough Joint Health and Wellbeing Strategy 2012-2015' to this call is through a variety of priorities. One area that could be given greater consideration and inclusion in the strategy is that of '**Dying Well**' and what this means to the residents of Rotherham.

In considering the 'Rotherham Borough Joint Health and Wellbeing Strategy 2012-2015', the Marmot Review and adapted 'Life Course Framework', there is also a need to respond to the JSNA in the light of the drivers found in other government's strategies. This feedback has considered the following government strategies, policies, other research and publications:

- Building a Stronger Civil Society (Office for Civil Society, 2010)
- Equity and Excellence: Liberating the NHS (DH, 2010)
- End of Life Care Strategy (DH, 2008)
- End of Life Care Strategy – Quality Markers for End of Life Care (DH, 2009)
- The NHS Operating Framework 2012/13 (DH, 2011)
- The NHS Outcomes Framework 2012/13 (DH, 2011)
- Dying for Change (Demos, 2010)
- Agenda for Later Life 2012 – A Summary of Policy Priorities for Active Ageing (Age UK, 2012)
- Quality Standard for End of Life Care for Adults (NICE, 2011)

The emphasis on building a stronger civil society where voluntary and community organisations are able to mobilise and support people is seen as an important element in achieving the reduction in health inequalities highlighted in the Marmot Review. Indeed, Marmot recognises the importance of the third sector: 'the evidence shows that partnership working between primary care, local authorities and the third sector to deliver effective universal and targeted preventive interventions can bring important benefits.'[2] Empowering communities, opening up public services and promoting social action[3] are all key themes of the government agenda for a 'big society' that mirror the Marmot review. The challenge is connecting these aspects together to deliver real choice, measurable outcomes and a reduction in health inequalities that delivers social justice in action.

To improve health outcomes the current changes to the structure of the NHS build on Lord Darzi's work that aims to 'discard what blocks progress...the overwhelming importance attached to certain top down targets. These targets crowd out the bigger objectives of reducing mortality and morbidity, increasing safety and ***improving patient experience more broadly – including the most vulnerable in our society.***'[4] One aim in the 'Rotherham Borough Joint Health and Wellbeing Strategy 2012-2015' must surely be to improve patient experience for the most vulnerable in our society approaching the end of their lives. Specifically, liberating the NHS should demonstrate increase of choice and control for end of life care and support people's preferences about how to have a good death and work with all providers to ensure people have the support they need.[5]

This aim is translated into the delivery of the NHS Operating Framework for 2012/13 with the aim of improving services for patients: 'putting patients at the centre of decision making in

preparing for an outcomes approach to service delivery, whilst improving dignity and service to patients and meeting essential standards of care'[6]. This move towards quality and outcomes will drive the change in culture required to reduce health inequalities.[7] We see this reflected in the NHS Outcomes Framework 2012/13 through the outcome 'Enhance the quality of life for people with long-term conditions' and the indicators that focus on providing support, enhancing the quality of life for patients and carers and also reducing time spent in hospital[8].

These themes resonate with the Marmot review hoping to empower individuals and communities with a vision of 'creating conditions for individuals to take control of their own lives'[9] and certainly matches the two policy goals[10] identified in the review. This is an essential part of reducing health inequalities and must remain an essential part of the Joint Health and Wellbeing Strategy for Rotherham.

With such emphasis it is easy to miss the simple fact that no matter how much we reduce health inequalities, we all die. The questions we should ask regarding end of life care are 'how do we improve dignity for patients?', 'how do we improve patient experience for the most vulnerable in our society?' and 'how do we empower patients to make choices?'.

What we can do as part of the overall Health and Wellbeing strategy is to consider '***Dying Well***' as an essential part of the life course framework.

Why include Dying Well?

Empowering individuals to take control of their lives and reducing inequalities applies equally to enabling people to make positive choices that help maintain quality of life towards the point of death and choices about where they would like to die. Improving an individual's quality of life can impact in terms of days, weeks, and months more before death, not just upon them, but upon those family and friends around them, reducing anxiety and stress for example, whilst reducing hospital admissions and crisis funding. We can equally see how the inequalities and the reasons for them highlighted by Marmot apply to how people die. It is not hard to see that those with more resources have greater power to determine the levels of care they may receive, when those with little or no resource are dependent upon the ability of society, the NHS, or other voluntary sector providers to deliver their care.

In 2008 the Department of Health published the 'End of Life Care Strategy – Promoting high quality care for all adults at the end of life'. This strategy gives emphasis to the delivery of high quality coordinated care that goes beyond the individual and their preferences for end of life care. It includes support for carers both before and after death recognising the social impact that can be felt through the loss of a loved one.[11] It recognises the inequalities that can exist at end of life for those who are able to access quality services and those who cannot, often the most vulnerable.

The Rotherham JSNA highlights challenges facing us locally through an ageing population[12] where incidences of loneliness[13], increased occurrences of dementia[14], increased death rates from smoking, alcohol and obesity[15], high rates of deaths through cancer[16], alongside a higher rate of hospital emergency admissions[17] all impact on where funding should be directed. To only tackle the health inequalities and provide funding in the Life Course Framework without consideration to the end of life will leave us with a legacy of an ageing and older population where inequalities will still be encountered. These inequalities can be

tackled by working together across Rotherham through collaboration of all partners, with improved and integrated care pathways that are well coordinated.

The Marmot review is clear: '***Services that promote health, wellbeing and independence of older people and, in doing so, prevent or delay the need for more intensive or institutional care, make a significant contribution to ameliorating health inequalities. For example, Partnerships for Older People projects have been shown to be cost effective in improving life quality.***'[18] These projects delivered reduced hospital admissions, provided rapid response services and improved the quality of the user's lives and also delivered improved partnerships between health agencies the voluntary sector.[19] Again this demonstrates the key role the voluntary sector has in delivering the Rotherham Health and Wellbeing priorities. It is able to mobilise society and bring added value into service delivery in a way that the public and private sector cannot.

The 'NICE Quality Standards for End of Life Care for Adults' are clear about the outcomes that end of life care should deliver: 'Enhancing quality of life for people with long-term conditions...that the care for people approaching the end of life received is aligned to their needs and preferences.'[20] Again this aligns with the aims of Marmot to allow individuals to take control of their own lives, at a time when this control can be taken away from them by the very nature of their disease. It promotes wellbeing and independence for older people and improves dignity and quality of life. This also matches the concerns of Age UK in their report summary 'Agenda for Later Life 2012 – A summary of policy priorities for active ageing' where they call for equitable access to provision, dignity and compassion in care, and the ability for older people to retain independence.[21]

Delivering the 16 quality markers[22] identified in the NICE standard for end of life care will begin to address issues of prevention and intervention that can impact on a reduction in the high rate of hospital admissions. It will empower individuals to take control and make choices and will ensure that the legacy of a holistic approach to end of life care continues well into the 21st century in Rotherham. This will enable us to address the issues highlighted in Rotherham's JSNA that will make demands upon our services if we make no response to dying well.

The voluntary sector has a clear role to play in delivering a 'Dying Well' life course element that pulls together the strands of differing agendas across health and social care. We can achieve this through partnership working and by responding to the call by Marmot for courage and imagination[23] to do things differently, to perhaps lay aside organisational differences and protectiveness and to deliver social justice[24]. This is the only way to ensure we reduce health inequalities across the Life Course Framework, up to and including the point of death.

This will mean creative and innovative approaches to delivering end of life care in an integrated and coordinated way that empowers individuals to make choices and ensures their dignity and control are maintained. It will mean providers of health and social care from public, private and the voluntary sector joining together to deliver social justice and reduce inequalities in end of life care and dying, and to ensure those in Rotherham who need the right care, receive it so they can die well. This integrated approach will reduce the need to provide funding at the point of crisis and flows with the prevention and intervention themes of Marmot. Directing funding in courageous and innovative ways will reduce inequalities, reduce

fire fighting, empower individuals, allow choice, retain dignity and enable people to experience dying well.

Including '**Dying Well**' as an additional element of the Life Course Framework for Rotherham will ensure the Rotherham Health and Wellbeing Board gives suitable priority and focus to end of life care in its broadest meaning.

"*Britain needs to create ways for people to live well even as they are dying, otherwise in the decades to come many hundreds of thousands of people will experience unnecessarily distressing deaths. We will die badly in places not of our choosing, with services that are often impersonal, in systems that are unyielding, struggling to discover meaning in death because we are not in surroundings that provide for intimacy and care and find ourselves cut off from the relationships which count most to us. Our challenge is to help people to achieve what is most important to them at the end of life. That will require the creation of a network of health and social supports so that people can die at and closer to home, with the support of their family and friends, as well as pain relief and medical services as they need them.*"[25]

"Rise up with me against the organisation of misery"[1]

References

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