Promoting Independence and Personal Dignity

Services should work towards supporting and maximising the wellbeing of the individual – ensuring that they live their lives as well as they can. The system should ensure that everyone (staff and users of the system) is treated with dignity and without discrimination.

1. Introduction

This report represents a summary of wide ranging discussion within the group at three meetings, and work by individuals between meetings. The proposals identified in this paper are not fully worked up, but do reflect those discussions, and the emerging views from the public consultation process. Clearly they do not cover all elements of the areas encompassed by the taskforce remit, and they do not have a full evidence base. However, they do present a view from the group on the areas requiring action and we present them to you for your consideration.

2. Working methods

The Group was keen to consider issues, and make recommendations, which would transform citizens’ experience. We took time therefore to understand and discuss existing shortcomings before considering proposals. A number of cross cutting themes emerged which were then tested against the three phases of need as described in the consultation – maintaining good health and well-being; entering the health and social care system when and where necessary; and navigating the system when using it. Issues were considered both in terms of the needs of the citizen and of the consequent requirements of the system. Much useful work has been put together which cannot be contained in this report but which will be available as a technical appendix. The Group found a lot of commonality in the fundamental issues no matter what the issue under consideration. Our proposals seek therefore to address these fundamentals.

3. Problems to be addressed

These are best illustrated by a real life situation:

Ms A is an elderly widow who moved to be near her son. She has an array of physical ailments associated with old age, including diabetes, which means her general state of health needs constant vigilance. Her son has a physical disability. Ms A already had limited mobility from a previous fall but her situation living at home was reasonably under control. Three months ago she fell again and broke her second hip. Experience of acute care was poor with minimal assistance to remobilise, limited pain relief provided and no physiotherapy offered. Assessment by social services on discharge was very limited with no mention of Ms A’s holistic needs. Ms A was discharged in a wheelchair with very restricted mobility. No arrangements were made for domiciliary physiotherapy despite family requesting it and explaining that Ms A cannot use a car to get to hospital and gets sick in an Ambulance, which takes her days to recover from. Limited home care was offered – 20 minutes in the morning to get Ms A out of bed washed and dressed, and 20 minutes in the evening to go to bed. With no physiotherapy to remobilise, Ms A gradually deteriorates both physically and mentally. She develops incontinence but despite requests for assistance and advice from her GP and Nurse only minimal support is given. She becomes very depressed from failing abilities and still
complains of being in pain. Her GP prescribes pain killers but does not review the situation himself or request a further assessment.

Home care proves unreliable. Late arrival in the mornings means that Ms A is not helped out of bed until midday on some occasions and several times the home carer arrived three hours late to put Ms A to bed. The family make complaints to a wide range of agencies including the home care agency which are ineffective. Ms A becomes increasingly depressed, is frequently sleeping, and is complaining of being in pain. She suffers a diabetic episode due to blood sugar levels falling. The GP and Nurse are called in who suggest that the time may have come for Ms A to go into a care home.

*If this white paper does nothing else, it must tackle the sense of powerlessness felt by many in our country in managing their health and well being.*

Put simply we see a requirement for change which:-

- Brings about true integrated, personalised care and support from health and social care services;
- Develops social capital in communities;
- Brings about a culture change in institutions, leadership and staff which shifts the balance of power towards the citizen in the relationship.

4. Proposals

**1) Local Strategic Partnerships & Community Based Commissioning**

Integration at the front line must begin with joined up Government. We believe that more needs to be done at inter-Departmental level to set coherent, holistic outcomes to local communities - using the Local Strategic Partnership - instead of the target driven culture that currently exists. The group felt that the key targets for the NHS channelled resource and managerial attention to the acute sector and made it hard for partners to engage with the NHS. The differential growth there has been in NHS and social care resourcing over recent years adds to this challenge. Local Strategic Partnerships (LSPs) in turn need to listen to local communities in setting outcomes and more importantly, give communities and service users more say in how these outcomes will be achieved. We believe that LSPs should be developed to take on a greater co-ordinating and delivery role, using the Local Area Agreement and backed by appropriate pooling of resources from mainstream funding.

To give local people a greater voice in meeting their needs and promote joined up services, we suggest the introduction of **Community Based Commissioning** (CBC). LSPs would take responsibility for leading and overseeing strategic direction and market management of the CBC and community provider system. Commissioning at this level would cover areas of life, health and service improvement that fit well on a neighbourhood basis. This might include:-

- Health Improvement – for example, diet, exercise, smoking cessation, alcohol, sexual health, breast feeding and screening services;
- Health and Local Authority Service Improvement – areas such as primary care, community services (eg podiatry, counselling), continuing care, domiciliary care, and ensuring coordinated care for those who need it on an ongoing basis;
• Life Improvement – areas such as citizens advice, benefits advice, community safety.

We suggest CBC sits alongside strengthened Practice Based Commissioning and commissioning for complex, specialist and intensive needs, such as for those with long term conditions, a learning disability or children with special needs.

In addition there needs to be some high calibre project driven programmes of work, working across health and social care and the voluntary sector, that could blaze the trail in developing more effective and efficient joined up services in the community for people at the end of their lives. This would enable a template for future planning and commissioning of end of life care.

In this way communities would be empowered to take ownership and address their own inequalities, which they understand better than agencies, in the way they see fit.

2) Expert Communities
This is integral to proposal 1. A community may be either geographic or defined by shared interest or aim. We need to mobilise communities to help themselves. Agencies and professionals should be ‘on tap’ to support them not ‘on top’ as currently is the case. We need to build on the social capital which already exists to enable communities to articulate and formulate their needs, and how these should be met, and to build local social enterprise to meet their provider requirements where appropriate. An expert community would have strong leadership based on promoting the wellbeing of all of its members; a clear understanding of pockets of inequalities within the community and the factors that contribute to this; a wide range of skills available to them from within; and a strong desire to improve the health and well being of the community.

Communities currently lack the investment to link up their expertise with action that makes a difference to the health and well being, of both the population and of the individual. Under the umbrella of the LSP, the NHS, Social Services, voluntary sector and other agencies must develop a belief that communities can solve their own problems when properly supported by experts; be prepared to hand over control to communities; commit resources to trusting and symbiotic relationships; support local staff to take risks and do things differently; develop less onerous and more meaningful performance monitoring which reflect changes within the community including well being; and be prepared to work in different ways and reconfigure services to meet the needs and requirements of the community.

Local Authorities should be responsible for developing, with local PCTs, a strategic needs assessment of the needs of the local population. Its purpose should be to inform commissioning and longer-term planning and to encourage providers to enter the market. LAs should be responsible for ensuring that there are sustainable conditions for providers, both large and small, to thrive. Issues such as planning, sites, utility costs, the workforce and the provision of information are key to this. Small scale providers, in particular, can offer an essential, informal and often lower cost part of the market especially in the care of individuals outside of hospital.

These measures collectively should enable communities to reverse the inverse care law.
3) **A contract with the User**

We believe there must be a fundamental change in the balance of power between the user and provider. An end must come to the ‘gift’ culture whereby the user is made to feel grateful for what he or she receives. At the outset of any episode of care, long or short, complex or simple, the user should have set out clearly what can be expected, including minimum standards, a description of the journey, including any choices, and their probable consequence, to be made. Wider information to raise citizen awareness of rights or indeed entitlement to what they may expect, is required. This could be through a publication like a ‘Which Guide to Health and Social Care’. The role of the expert community could include development of community based information resources and support through development of Community Advocates who would support and advocate for the vulnerable, including marginalized groups such as homeless people and ex-offenders. Clearly setting out and publicising what users may expect would help navigate the system. The support of special needs groups and of those whose voice is not heard, for example children, needs to be especially addressed through their community of interest. We see scope for an extension of current liaison and advocacy services, more embedded in the community, to manage a local single portal for advice and support on a telephone line nationally known but routed to local support. This portal should be the responsibility of Local Authorities, bringing together services that impact on the wellbeing of communities, including for example housing services as well as health and social care. Its aim should be to make entry into the system more simple – people need to be able to make sense of the wide range of information and services available and ultimately to secure the information that they need to make real choices about their future care. We see this as a key priority. Access for those who cannot use a telephone through language or disability barriers must also be considered, again through their community of interest.

4) **Changing Institutional culture**

Providing the right infrastructure for promoting independence and personal dignity by facilitating local partnership and community empowerment, and delivering personalised care, will require a fundamental shift in the culture of organisations, the staff within them, and those who lead them. Moving to a trusting, supportive relationship where the citizen or user exercises a greater degree of informed choice will not rest easy with professionals. Throughout our discussions the Group spoke of the need for **humanity**. We considered that this lack of humanity exists because organisations allow it to. Change must start with the ethos and culture of Boards and their leadership and we recommend that a set of values be shared across health and social services to underpin the White Paper’s commitment to promoting independence and personal dignity and tackling discrimination of users and staff. This must then be embedded in the core competencies required of Board members and leaders. Personal development and performance review of Chief Executives should switch emphasis towards achievement of these values.

We believe that staff training, be it organisation leaders, senior clinicians or receptionists, needs to emphasise from induction, customer care principles such as politeness, respect of privacy, and respect of citizen judgement. Throughout our organisations we need to learn how to let go, yet maintain standards of clinical and non clinical governance. Joined up Government needs to support true partnership working by leaders out in the field.
5. Priorities for action
To summarise we believe that the White Paper should include the following priorities for action:-

- Develop further, joined up Government through the LSP and Local Area Agreement;
- Develop Community Based Commissioning;
- Reposition Health and Social services and Government Agencies to support and develop expert communities to support the citizen and let go of decision making to those communities;
- Introduce a national telephone number (portal) that is locally routed, which improves understanding and makes entry into the health and social care system easier, as well as signposting to other services relevant to the wellbeing agenda;
- Ensure services for people with complex needs and those at the end of their lives, and the commissioning of those services, are suitably developed and joined up to enable effective care in the community of our most vulnerable citizens;
- Change culture and ethos from Government down.

Derek Campbell
Chair, Independence and Personal Dignity Policy Taskforce Group

Annex A gives a list of group members

A technical appendix to this report is available.
Annex A
Promoting Independence and Personal Dignity Taskforce Group members

Chair : Derek Campbell (Liverpool PCTs)

Mario Ambrosi (Anchor Housing)

John Knight (Voluntary Organisations Disability Group)

Lucy Sutton (National Council for Palliative Care)

Ann Mackay (English Community Care Association)

Sharon Hassall (Marie Curie Cancer Care)

David Congdon (Mencap)

Harold Bodmer (Norfolk County Council)

Rachael Childs (Help the Aged)

Sir Nick Young/Liz Urben (British Red Cross)

Heather Wing (General Social Care Council)

Mona Sehgal (LGA)

Yvonne Doyle (DPH, SHA)

John Dixon (ADSS)

Lalit Kalra (King's College Hospital)

Christine Lenehan (Council for Disabled Children)

Richard Thompson (Greenwich Council, Housing representative)

Terry Lewis (User representative)

Sue Welsh (AHP representative)