

Consultation Event on DH Commissioning Framework for Health and Well-Being

25 May 2007



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Introduction – Health Link welcomes the opportunity to contribute to this consultation, especially as our remit is to facilitate and encourage community self help on health inequalities and community involvement in health services giving us a strong focus on involvement in commissioning. Our response is developed from a Consultation Event we held on the Commissioning Framework for Health and Well-being for our Network (see below). This was attended by 17 members of the Health Link Network. Up to 45% of the participants were from Black and ethnic minority groups and were residents of 10 London boroughs

About Health Link: Health Link is a not for profit social enterprise established in January 2004. Our aim is to help *all* communities become active agents in improving their own health by linking them to

- the bodies which control the *determinants of their health* and
- the NHS which controls the *quality* of their health services

We have a patient and public involvement pan-London Network of 125 patient representatives across 31 London boroughs, some of whom are also members of the North West Patient Parliament, or Patient Forums across London.

What do we do? Since the Bristol Enquiry (2001) and the Wanless Report (2002), patient and public involvement (PPI) has been seen as crucial for a patient-centred NHS. However, there are challenges to making it a reality, particularly for patients who suffer health inequalities. In its first three years, Health link has worked on some of these challenges:

- PPI in national policy implementation
- PPI to influence strategic decision-making
- PPI to help shape choice policy around health inequalities
- PPI to help commission materials to support patients in Choice
- PPI to help the NHS design services around health inequalities
- PPI in the determinants of health
- PPI in specialised services: until December 2006
- PPI in cross-sector working on health (Referral and signposting pathway for Homeless People)
- PPI in cross-government working (Partnerships for Patients)
- Using PPI to connect Patients' Forums to their communities
- Training in PPI and outreach PPI

The Consultation Event: Rather than ask some of the rather detailed questions in the consultation, we approached the consultation from a lay person's point of view by asking ourselves and the participants the following question:

'How can local health and social care services promote health and well-being?'

The discussion then focused down on two of the scenarios used by the Department of health in the consultation document's foreword, Doris and Sunita, with small group work.

1. General Discussion

1.1 Existing shortcomings in care: commissioning at local level could lead to shortcomings in care which needed to be co-ordinated across London, for example Stroke services. Participants felt that the proposed local commissioning model would not solve service problems for such illnesses. There are very few hospitals have a dedicated stroke unit and higher death and morbidity rates as a result. Proposed solutions include the need to commission London wide services for illnesses such as stroke and improved after care for stroke sufferers.

1.2 Physical healthcare for Mental Health Service users: it was noted that mental health services fail their users by not always catering sensitively for the patients' physical needs.

1.3 Volunteering within the health services: there is increasing focus on the role of volunteers in supporting patients and in getting involved in patient and public involvement, whether as carers, advocates or patient and public involvement activists. For example, to support a service user with the implementation of Direct Payments was ludicrously complex and akin to running a small business. The NHS needs to attach more value and appreciation to the services provided by volunteers, particularly volunteers who receive income support. Volunteers find problems when trying to justify the money given to them as volunteer expenses when they attend job centres and this is a disincentive. It was generally agreed that health services need to recognise that there has been a shift from the traditional volunteers who were women that have since got into full time employment to older people (as volunteers) who now live longer because of better health provisions.

1.4 Social care: to support child carers there is a need to join up information from social services with that of education. This would limit the number of young people who end up as carers for their parents, a scandalous state of affairs.

1.5 Transport: there is sometimes inflexibility in community transport allocation with carers not being permitted to travel with patients.

1.6 Proper coordination between social services and hospitals: It was generally agreed there needs to be better links between social services and hospitals, particularly for patients leaving hospital. Participants felt that there was a low follow up on patients when discharged and left to the local authorities. This was a particularly worrying trend given the vulnerability of these patients

1.7 Hidden Needs: there are many hidden needs of service users, such as those of child carers. These can only be understood if there is good and timely involvement of those users. Direct Payments was an example of an innovation which could have been designed much more realistically with appropriate user involvement.

2. Services - What do 'they' need to do to make services work better?

Questions looked at in discussions

- Are there better solutions for Doris or Sunita?
- What are the barriers to achieving what Doris or Sunita really needs?
- What about older people generally?
- What about disabled people, people from ethnic minorities or carers?

Case study - Sunita

Solutions

Above all, Sunita should be asked what she wants and be empowered to make decisions about her health and well-being.

- This might be through taking her to centres that house people with similar disabilities to see how they go about increasing their independence.
- The parents should receive enough information about services
- Social services should not professionalise services, but personalise them
- There should be more accountability and monitoring for the services provided to the patient, involving users and their representatives
- Choice for Carers for people such as Sunita take into consideration the language needs, age group as well as their faith
- Professionals giving information should check to see whether the individual receiving this information actually understands it

Barriers to improving services

- Bureaucracy
- Constraints on capacity of services i.e. social services, G.P and hospital staff.
- Time and money to provide adequate care
- Transport inflexibility (older people)
- Lack of access to public transport for disabled people in particular
- Lack of coordination between social services and health services- (deficits were a disincentive to joint working)
- Having to complain in order to obtain a service

Case Study – Doris

Solutions

- Doris's first requirement is probably social contact with people she can trust. This is the single most important thing in making her confident and empowered to express her needs and wishes.
- Personal control: so many care locations for vulnerable older people take away the most basic freedoms, such as deciding when you want a cup of tea rather than being given one at a fixed time everyday.
- Doris needs to be involved in service planning and monitoring –ask her what she wants
- Working more closely with faith groups so they facilitate involvement and access to services.

Barriers

- Lack of a personal relationship with paid carers, who may change frequently and have little time to talk
- Personal reticence from Doris – social contact would enable her to compare notes with her peer group and gain confidence to express her views
- Means testing as a stigmatising experience
- Social isolation
- Failing skills such as the gradual loss of confidence in basic domestic tasks such as making a cup of tea, difficult to capture early enough to address.
- Support to get benefit entitlements
- lack of respect for people as *individuals*, rather than as batch of needs

Systems how can be held 'they' be held to account by service users?

How can commissioning be influenced by patients?

- Commissioners should recognise 'hidden needs'
- Commissioners should realise that the traditional information routes such as leaflets may not always offer the best sources of information. Word of mouth is often as effective
- Information could be kept online and printed off when needed.
- Need to commission services that take into account both the mental and physical needs, particularly for mental health service users.

Conclusion

There were two particularly important themes to emerge from the Consultation Event: the recognition that vulnerable people often have hidden needs and that the only way to really give service users what they need is to involve them effectively. Involvement of Sunita and Doris is obviously a challenge. It might be possible to involve volunteer advocates to seek their views sensitively. However, this will not be possible with the current rather exploitative approach of some in the statutory sector to the role of volunteers. In the same way there must be strong user involvement in monitoring whether what is commissioned actually meets users' needs.

**Consultation Event on Department of Health's
Commissioning Framework for Health and Well-Being
Aneurin Bevan House, 81, Commercial Road London E1 IRD
Friday 25th May 2007 11am-3pm**

AGENDA

1. Welcome and Introductions

2. The Problem: *How can local Health and Social Care Services promote health and well-being?*

Presentation from Elizabeth Manero, Director, Health Link

3. Questions and Discussion

LUNCH

Small Group Work

4. Services: What do "they" need to do to make services work better?

Case Study One: Doris

- Are there *better solutions* for Doris?
- What are the *barriers* to achieving what Doris really needs?
- What about *older people* generally?

Case Study Two: Sunita

- Are there *better solutions* for Sunita?
- What are the *barriers* to achieving what Sunita really needs?
- What about *disabled people*, people from *ethnic minorities* or *carers*?

5. Systems: how can "they" be held to account by service users?

Case Study One: Doris

- How to give Doris *influence on commissioning* (planning) of services

Case Study Two: Sunita

- How to give Sunita *influence on commissioning* (planning) of services

6. Summing up and next steps

EM

Appendix 2

Attendance list for the Consultation Event

1. Victoria Adophy
2. Chris Baker

3. Margaret Bell
4. John Bell
5. Pat Healy
6. Jill Iremonger
7. Davinder Kaur Barbra
8. Etta Khwaja
9. Faridoon Madon
10. John Murphy
11. Clarissa Rocke-Caton
12. Brenda Rosebrey Jones
13. Balan Sisupalan
14. Margaret Summers
15. Gerald McMullan
16. Myra Garret
17. Viorica Bergman
18. Elizabeth Manero
19. Jenny Sharp
20. Katarzyna Hadjuk
21. Anthony Sembatya