

Local Involvement Networks (LINKs) Bulletin issue 4 – June 2007

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Gateway reference 8520

About this bulletin

This bulletin is of particular interest to:

- NHS staff working on Patient & Public Involvement programmes;
- Local Government staff working on user involvement programmes and the procurement of LINKs;
- Local authority health and social care overview and scrutiny committee members and support staff
- Voluntary and community sector organisations which are interested in providing a 'host' service to the new LINKs or becoming a member of a LINK, including those that provide forum support services;
- Current PPI Patients' Forum members; and
- Health and social care regulatory bodies with PPI interests
- People involved in user groups which focus on health and social care related issues

We ask that you forward the bulletin to all members of your team, colleagues and friends who may benefit from this information. You may wish to print and display this bulletin on all relevant notice boards or arrange to have it published on your internal intranet sites.

Website links

If you are reading a printed copy of the bulletin, you may not be aware that further information is available on most items on the DH website. You can access the online version of the bulletins along with further information and links on PPI issues at:

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/fs/en>.

Feedback

We welcome your ideas and comments that will shape the format and content of this bulletin in the future. We have received requests to provide future versions of these bulletins in larger font format. We have been listening to these requests and are sending this and future editions out in a larger font. The next edition will be published in July 2007. Please e-mail

ppimailbox@dh.gsi.gov.uk or write to the PPI Policy Team, Room 502A, Skipton House, 80 London Road, London SE1 6LH.

Introduction

Welcome to the June edition of the LINKs bulletin. This edition is focusing on social care.

TOP STORY

Health and social care – so what is really the difference?

There are some obvious similarities between health and social care, not least the overlap in the population of regular users (older people, disabled people). However, there are some important differences. Social care is not a universal service; it is means tested. For the majority of people, use of health care is an intermittent activity. Social care is usually a more ongoing need.

Social care increasingly reflects the social model of disability, focusing on removing the barriers to people's social and economic participation. This approach does not always translate well under a healthcare model, which is about making the individual better or rehabilitated.

Within social care there is increasing experience of services that are designed and managed by the people who use them and this demonstrates a model for genuinely devolving power. Current initiatives are giving individuals the capacity to purchase their own care and design their own structures of support outside the health and social care professions, a different but significant form of 'involvement' (for more information go to www.in-control.org.uk or www.individualbudgets.csip.org.uk).

What do we know about what works

The Joint Participation Steering Group is a network of national organisations in health and social care, working to promote best practice in involving people in service design, delivery and regulation.

The JPSG has adopted a set of principles to guide the work. Members of the group agree to

- be clear about the purpose for involving people who use services and their families in aspects of work
- work with people who use social-care and health services to agree the way they get involved
- let people who use services and their families choose the way they become involved
- exchange feedback about the outcome of people who use services and their families involvement in appropriate ways
- try to recognise and overcome barriers to full involvement

- make every effort to include the widest possible range of people in our work value the contribution, expertise and time of people who use services and their families
- use what we have learned from working with people who use services and their families to influence changes in our ways of working, to achieve better outcomes.

In practice this means:

- ✓ working to involve people from the beginning of any process, not half way through
- ✓ planning creative ways of involving people – not just meetings and groups
- ✓ Setting aside an adequate budget to allow for information to be made accessible to people and for paying people for their time where appropriate
- ✓ dialogue with colleagues to ensure they are aware of the benefits of involvement, and use the outcomes of involvement.

“Shaping Our Lives is an independent national user controlled organisation and network that is made up of and works across the wide range of long term users of health and social care services, including mental health service users/survivors, people with learning difficulties, older people, people with physical and sensory impairments and others. Over the ten years we have been established, we have learned some valuable lessons from the experience of many service users and supportive practitioners and agencies. First, the key route for people to gain the confidence and capacity to get involved effectively is through linking up with a local user-led organisation. Over and over again, people highlight this as the key starting point for their empowerment. Second, we’ve learned the importance of making possible *diverse* involvement – enabling everybody whatever their impairment or experience to be involved on as equal terms as possible. That means developing effective policies for access – physical, communication and cultural access and moving beyond traditional paper, speaker, meeting based approaches to involvement. Getting involved should be a positive, enjoyable experience. Most of all it needs to be audited in terms of how much positive change it brings about for service users.” Further information on ‘Shaping Our Lives’ can be found at: <http://www.shapingourlives.org.uk>

Peter Beresford
Chair, Shaping Our Lives

Speakup Self Advocacy is an organisation that employs people with a learning difficulty as self advocates. Our aim is make services better in the region and beyond for people with learning difficulties. When people or organisations ask us to get involved and give our opinions, funding us properly is very important, as without it we wouldn't be able to run Speakup as good as we have been able to do. Here are a few quotes from Speakup members about funding and what it means to them:

"I think that it is important to get adequate funding to back-up the self advocates work. Without funding we would have great difficulties running our organisation and paying the advocates and the supporters, but also we need funding to get to meetings and conferences to do our self advocacy work."

"We have one of the highest employment rates in Rotherham and we are an employer of learning difficulties people, without adequate funding we would no longer be able to keep this level of employment up"

Jonathan Evans

Self Advocate
Speakup trainee journalist

<http://www.speakup.org.uk/>

Example 1

Experts by experience in inspection

The Commission for Social Care Inspection (CSCI) uses 'Experts by experience' in local inspections. The experts, who have all had direct experience of using services as disabled people or family carers, are supported by voluntary organisations.

Essex Coalition of Disabled People is a supporting organisation for the Eastern region and will be coordinating the work of 6 experts until March 2008.

The experts will be carrying out inspections in partnership with the Commission for Social Care Inspection (CSCI) who register and inspect social care services in England and make sure they are doing what they should.

The Experts, the people who have experience of social care services, will be helping CSCI to change the way it inspects and provides information.

The value of this to CSCI is illustrated in the comments from a recent evaluation of the scheme:

“I found this to be a valuable part of the inspection. It was useful to have feedback from a person with lived experience - I felt that the views expressed to her by the service users were genuine comments” (Provider)

Experts by experience bring not only their personal knowledge of using services. They quite often have specific skills as disabled people or family carers that they bring to the process, too.

“She came prepared with pictorial tools for engagement with service users with no verbal communication. She engaged with other service users about their life experiences.” (Inspector)

What this means for LINKs

Disabled people’s organisations have real expertise to offer to commissioners, providers and regulators.

Example 2

Direct payments support

Direct payments are cash payments in lieu of services, available as an alternative to social care services and were developed by disabled people themselves. Direct payments are an example of how people who use services can directly participate in the management of services. Most people use the money to employ someone to help them at times and in ways they choose. Most localities have a support organisation to help people use their direct payments effectively and these are often user-controlled organisations. They develop a great deal of knowledge of what works.

One such organisation is Cheshire Disabilities Federation (CDF):

“Through the delivery of its contracted services and projects, CDF has noted the emergence of informal 'peer' support networks amongst neighbouring individuals in rural and isolated communities (both of area and kind). These networks would seem to offer a model for empowering individuals to better manage their direct payments as well as acting as an informal recruitment agency for care givers, thus enhancing the value of care purchased with direct payments and enhancing the value of employment opportunities for local carers.”

What this means for LINKs

LINKs will need to channel this sort of knowledge from people who use services and their families towards commissioning bodies, so that it becomes a part of local resource planning.

Example 3

Support for young people (Bristol)

“We believe that young Disabled people should be included in all aspects of life alongside all other young people. Some young Disabled people require assistance so that they can be included on an equal basis. Youth PASS is a scheme that exists to promote inclusion through the provision of effective personal assistance.

The scheme enables young disabled people to use a personal assistant, and to have more freedom to get out and about, and to become more involved in community life (for example joining youth groups, shopping, meeting up with friends).”

Source: West of England Centre for Independent Living

What this means for LINKs

For some groups, inclusion requires long term and detailed planning. LINKs will need to work with groups such as the YouthPASS in order to include young disabled people successfully.

Example 4

London Older People’s Assembly

This year's event will be themed around environmental issues, and will offer older Londoners the opportunity to discuss practical ways to make a difference - from energy efficiency in the home to direct campaigning. An intergenerational debate will look at how younger and older Londoners can best work together to become more environmentally aware, and a "learning from our neighbours" seminar will see what positive examples other parts of the country have set.

What this means for LINKs

Older people have been very clear that they want to be involved on the basis of being people – with all sorts of interests – not pigeonholed as ‘users’ of the services that support them. Ensuring good links between social care and the wider community is part of the role of the Director of Adult Social Services.

If people are to be involved in influencing commissioning in social care they need to be able to influence the shape of all community services, not just those with a 'care' label.

Example 5

Person centred planning

Person centred planning helps people make the changes they want in their lives. When people with learning difficulties choose to plan by having meetings they work with individuals called facilitators.

Facilitators must have been trained to help people to plan. The facilitators help the person decide what is important to them and how to make it happen.

The 'Did it work for you?' project looks at how well person centred planning works for people with learning difficulties in Leeds and Bradford. It looks at the whole planning process and how people's lives changed because of it. The project was carried out by two people with learning difficulties (Sam Guyatt and Michèle Dore) working for Connect in the North as researchers in March 2005.

"We are paid to find out how good person centred planning is for people with learning difficulties and tell others what we find."

What this means for LINKs

People who use social care services are already experienced at evaluating them. LINKs need to draw on this knowledge.

Useful websites	
Social Care Institute for Excellence	http://www.scie.org.uk/participation/index.asp
Shaping our Lives	www.shapingourlives.org.uk
Speak Up Self Advocacy	www.speakup.org.uk

Developing effective relationships with LINK's – a social care perspective from the Manchester Early Adopter site:

There is a potential big win with LINKs: the focus on adult social care as well as health means the LINK will have a positive impact on people who use services and their families and the public more generally by making the connections between health and social care need, and commissioning of services. From the emerging work in Manchester, they think the LINK will have a substantial impact on the Council's Adult Social Care department, in that it will be a new stakeholder in commissioning; on social care providers (most of whom are independent of the council); and on existing representative groups for people who use services and their families, which have a lot of experience to offer.

The Manchester EAP think it is important, as the LINK evolves, to ensure that there is an equal emphasis on both health and social care given the increasing focus of Adult Social Care departments on intervention and prevention, healthy living and reablement. The priority is to assist more people into, or back into, independent living, education and employment. The potential strength of the LINK will be to keep focussed on what people want from their services and how to ensure that this informs the commissioning of service providers. In this, the LINK's perspective should reinforce at a strategic level people who use services and their families' individual choices.

Manchester want to ensure that the LINK builds on existing social care consultation fora. As a first step, they need to map out how the LINK will fit in with Manchester Adult Social Care's existing approach to people who use services and their families' consultation and engagement in service design, whether in needs analysis, decision making about services, or feedback on actual services delivered.

There are a number of existing active mechanisms for consulting and involving people who use social care services and their families in Manchester. For example, in Manchester, the Physical Disability and Learning Disability services have established partnership boards with people who use services and their families, who have a key role in taking lead responsibilities for linking with other organisations. They also hope the LINK will build strong connections with the Joint Health Unit and the Valuing Older People team. The existing networks that Adult Social Care already has can be used by the LINK in developing a strategic perspective from discussions with people who use services and their families.

Hertfordshire Early Adopter Project

Being an Early Adopter is proving an exciting opportunity in Hertfordshire.

Hertfordshire County Council Adult Care Services have a good track record for ensuring there is a wide range of ways people who use services and their families can share their views of services. As well as Having Your Say Forms (2,500 returned last year) and face to face visits by Quality Monitoring Officers (Homecare) and the Black and Minority Ethnic Involvement worker they run many forums and work closely with partners like Carers in Hertfordshire, Age Concern and POhWER (the advocacy agency). In addition joint commissioners have recently commissioned groups of service-users and carers to help to involve users and carers in the commissioning process.

The key now is to work with partners to develop a network that can be picked up by the LINK, once established, and run with.

Hertfordshire are also very keen to see that the new LINK has the IT capacity to collate and analyse data in a meaningful way to show that people involved truly represent the whole community profile. Clearly this will depend to some extent on the available resources.

They are increasingly experimenting with different outreach methods (on-line video clips, web-casting, working with the review of commissioning for people with physical disabilities and sensory service users etc), to make sure all can make a meaningful contribution. At the same time their work continues with more traditional methods, for example working with Age Concern on older people's forums.

The true challenge for the LINK will not be on accessing voices from the community, but making sure that there is a balance in the way they are sought and heard. Hertfordshire say the Board in the new structure must have an open and transparent debate about how to prioritise the work of the LINK in accordance with the most urgent issues. The finite resources will have to be managed in a way that is both fair and clear and the skill will be to find enough generic issues to keep all involved, while at the same time focusing on the urgent and topical specifics that will concern certain groups.

Hertfordshire are having a stakeholders conference on 20 September. They are planning to focus initially on examples of where people who use services and their families have had a positive impact on health and social care services as a way of encouraging further voices to be heard as they move towards the new structures.

News in brief

The Local Government and Public Involvement in Health Bill

The Bill received its second reading in the House of Lords on 20th June. Committee stage is expected to be sometime in mid July.

LINKs regional events

All nine regional events have now successfully taken place around the country.

The Department's PPI Team is still collecting all of the write-ups from each of the events and will use them in preparing further publications over the Summer and the guidance being produced once the Local Government and Public Involvement in Health Bill receives Royal Assent later in the year. We are also putting together details of the most common and agreed upon issues, which delegates voted the most important following each of the workshops. This document will be placed on the Department's website soon.

The transcripts for these events can be found on the DH website at <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/PatientAndPublicinvolvement/index.htm>.

NHS Centre for Involvement - contributions from all those involved in preparation for LINKs

We have received comments from readers of previous bulletins saying that whilst reading about progress from the EAP sites is helpful, it would be interesting to hear about progress being made in other areas of the country as well.

We have discussed this with the NHS Centre for Involvement, and encourage you to submit to the Centre examples of presentations, write ups from events, notable practice and experiences that you have had in preparing for LINKs. At the moment, the Centre can provide you with examples such as the report from the Durham LINKs Early Adopter Stakeholder Event which you can use and adapt to suit your own needs.

You can access these by going to www.nhscentreforinvolvement.nhs.uk and clicking on Local Involvement Networks and then 'What's New'. Please note that these examples are not meant to describe how you should be working - they are there to share information on what other people are experiencing.

If you have any documents that you wish to share with colleagues, please email them to nhscentreforinvolvement@warwick.ac.uk with a paragraph which describes the highlights of your submission.

Effective Consultation – Reviewing the code of practice on consultation

The Minister for the Cabinet Office and Social Exclusion, Hilary Armstrong MP, launched a review of the Government's consultation policy on Thursday 14 June. The centre-piece of this review is a paper entitled "Effective Consultation: asking the right questions; asking the right people; listening to the answers" and can be found at:

http://www.cabinetoffice.gov.uk/regulation/consultation/policy_review/index.asp

This paper seeks views on how the Government can improve its consultation processes. The Cabinet Office is seeking input from the widest possible range of organisations and individuals and will be grateful for your responses, and for any action you may be able to take to alert your own groups of stakeholders.

In addition to submitting formal responses to the questions in the document, stakeholders may share views on a discussion forum at

<http://haveyoursay.cabinetoffice.gov.uk/regulation/>.

More information is available at www.consultations.gov.uk. "

Next month's bulletin

July's bulletin will focus on 'A Stronger Local Voice' one year on and will include articles the pending publication of 'What an effective LINK looks like' and the 'model contract specification'. There will also be features on what the powers of LINKs will be and notice of the consultation on the regulations on LINKs' powers.