

# Local Involvement Network (LINK) in Barnet Conference Report



8 July 2008

## Introduction

### Councillor Helena Hart- Cabinet Member For Public Health

Councillor Hart welcomed all those present on behalf of herself and Councillor Lynne Hillan, Cabinet Member for Community Services. She explained that Barnet Council had organised the event as part of its transitional duties and to help bridge the gap before a Host was in place. The purpose was to get a nucleus of potential LINKS members – especially including those who have never been involved before – together to hear more about LINKS and the opportunities they provide, discuss the type of issues with which the LINK will be involved and encourage people to get to know each other.

She outlined how her Cabinet position fulfilled the Council's local leadership role in health and entailed working with partners such as the PCT, local NHS Trusts and the Voluntary and Community Sector to improve health - and health services - for local people.

People in Barnet lived longer than average but key issues were about the quality of patients' experience and the quality of their life, hence the focus of the new health and well-being strategy being 'adding years to life and life to years'. The LINK would be integral to achieving those aspirations.

She thanked all those present who had been active in Patient and Public involvement Forums and their predecessors the Community Health Councils for their admirable work, and welcomed those who had recently come forward through other mechanisms such as the Council's website, the Civic Network and the 55 plus Forum. She ended with a plea for everyone attending to continue to be involved, as health and social care had such a major impact on the lives of people and their families.

## Introduction to Local Involvement Networks (LINKS) and the opportunities they provide

### Jayne Taylor-Director of Organisational Development and Learning, NHS Centre for Involvement

Jayne Taylor made a presentation on what LINKS were and what they would do. She explained that LINKS were designed to

- give everyone the chance to say what they think about their local care services
- give people the chance to check how care services are planned and run
- feedback what people have said about services so things can change for the better.

She emphasised that one of the main purposes of LINKS was to give local communities more of a say in how health and care services were provided, particularly sections of the community that had not been reached before.

#### Among the powers of LINKS would be to:

- enter specific services and view care provided
- ask commissioners for information about services and expect a response within a set amount of time
- make recommendations and expect a response from commissioners
- refer matters to the local Overview and Scrutiny Committee.

Her presentation also explained the role of the host organisation in establishing the LINK and providing advice and support to LINK members, as well as reporting back to the council and wider community.

Questions were asked from the floor on board representation, and the role and status of Foundation Trust members. Jayne replied that these were the types of governance arrangements that the LINK needed to agree on, through the host, when established.

In response to a question on what role the LINK might have in monitoring any privatised health care, she explained the remit LINKS would have, and that people should stay involved with the LINK as one of the opportunities for influencing healthcare. Jayne was thanked for giving up her time to attend the LINKS Conference at short notice.

*'I wanted more information on LINKS- for example how would you handle 2000 members?'*

*(Note: the quotes in this document are the comments of delegates taken from their feedback forms)*

## Links in Barnet-Progress update

### **Andrew Nathan- Policy and Partnerships Group Manager, Barnet Council**

Andrew Nathan briefly gave information on progress to date in establishing LINKS in Barnet and explained that the Council and health partners were committed to maintaining and improving opportunities for involvement and engagement while LINKS were being established. The Council's Cabinet Resources Committee on 22 July 2008 would be making a decision on the appointment of a host. In that context he explained the purpose of the Conference was to bring interested parties together to prepare for a LINK being established and he agreed to maintain arrangements to ensure those attending keep in touch, both with the Council and with each other.

### **Where we see LINKS helping us - presentation by health and social care agencies in Barnet**

Some of the major health and social care providers and commissioners in the borough made brief presentations on the value of public involvement in their work and opportunities for LINKS members to get involved:

### **Andrew Burnett, Director for Health Improvement, Barnet Primary Care Trust**

Andrew Burnett explained the size of the PCT's budget and range of services and explained that as part of the Joint Strategic Needs Assessment of health and social care the Council and PCT was undertaking, more information was needed about what local people felt was important. Resources were finite and therefore the LINK needed to help the PCT through having a say in how services were prioritised.

### **Councillor Lynne Hillan, Cabinet Member for Community Services, Barnet Council**

Councillor Hillan welcomed the extension of the remit of the LINK into social care matters and highlighted the role that Scrutiny committees would have in considering what LINKS had found and how to respond. This was a logical reflection of the fact that Social Care services already worked closely with health. Indeed all social care matters required a partnership approach as more resources were being placed in the hands of individual service users, and there was a multiplicity of providers- for example most care homes were in the independent and voluntary sectors. The Council welcomed feedback and looked forward to the LINK host and membership developing ways to help the Council improve social care services.

## Ian Clift, Director of Nursing, Barnet Enfield and Haringey Mental Health Trust

Ian Clift explained the role of the Mental Health Trust in meeting the needs of a very vulnerable client group.

The Trust had valued their partnership with the former PPI Forum and this had been successful in improving services. In the future, they would welcome comments from the LINKS on consultations and service improvements in the mental health services the Trust provided, on their Annual health Check, and on quality issues relating to the Trust's services.

## Kay Laurie, Deputy Director of Patient Experience, Barnet and Chase Farm Hospitals Trust

Kay Laurie introduced her role as being to ensure that patient involvement was integral to the Trust's services and that they did not just pay lip service to it. They had established a Patients Plus Forum, and the former chair of the PPI Forum was still a participant in Trust Board meetings. She reported that the consultation on the clinical strategy for Barnet, Enfield and Haringey had been referred by the Secretary of State to an independent reconfiguration panel who would make recommendations. In future local agencies would have more responsibility in designing their own services which were responsive to local needs.

She also reported that the Trust were about to launch their patient Experience Strategy covering areas of importance to patients such as dignity, cleanliness and communication.

*'It is hard to see at this stage how LINKS will work but you have to make a start'*

## Links And Scrutiny Committees

### Councillor Sachin Rajput, Chairman of Supporting The Vulnerable Overview And Scrutiny Committee

Councillor Rajput explained the remit of the Overview and Scrutiny Committee in relation to promoting the well-being of all residents and its purpose of reviewing policy internally and externally, looking at both the NHS and Social Care. He invited all those present to work with his Committee via LINKS with a view to allowing for patient experiences to be considered through that forum when the LINK is established.

There was a question from the floor about a previous perceived failure a while ago concerning the Committee not following through with the making of a recommendation to write to the Secretary of State on a particular matter. Councillor Rajput advised that he was not

Chairman at the time of the alleged incident but asked if the person sought the issue to be looked into: this was declined.

Councillor Rajput stated that the Committee under his Chairmanship would have no hesitation in writing to relevant persons including the Secretary of State on appropriate matters and indeed he cited as an example the recent work in relation to the Independent Reconfiguration Panel concerning Barnet, Enfield & Haringey seeking to jointly refer a matter to the Secretary of State in relation to current matters concerning Barnet & Chase Farm Hospitals.

### ‘Health and Care Needs- Managing your own long-term conditions’

**Andrew Burnett, Director For Public Health, Barnet PCT and Expert Patients**

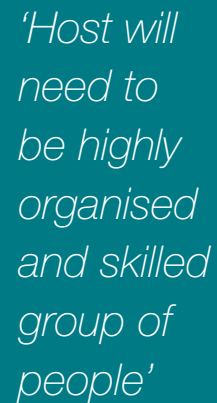
Andrew introduced the presentation by explaining that the medical professional needed to reflect people's needs- including dignity, safety and access to services, and provide information accordingly. However over the years there had been a shift in emphasis to reflect that the fact that patients knew more than their doctors about the reality of having a long-term condition, and this was reflected in the fact that communication with patients now formed an examined part of medical students' training.

*‘As an ordinary member of the public I hope I can make a difference’*

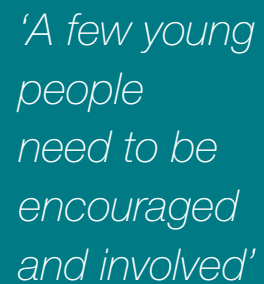
The expert patient programme was designed to help people know more about their conditions, and Andrew saw LINKS as having an important role in enabling members of the public to get the right information from the professionals.

Andrew introduced Sylvie Cronick, who had been diagnosed with progressive Multiple Sclerosis, but spoke of her experience initially with the MS Society and latterly training to be an expert patient tutor, and the positive difference it had made to her life. Russell Reuben, who also lived with MS, spoke of his experience in using the scheme which had offered valuable information in coping with everyday life, such as exercises to manage breathing and stress, and had given him a positive attitude to overcome the issues he faced.

Andrew set those present a challenge as to how more people could be involved in the scheme. In response to questions, he confirmed that some places on the programme were given to people with mental health conditions, and this needed to be more widely publicised. The expert patient scheme programme was also potentially very useful in helping people to prepare for outpatient consultations in terms of knowing what to say and how to say it.



*'Host will need to be highly organised and skilled group of people'*



*'A few young people need to be encouraged and involved'*

## Workshop discussions

### At workshop tables people were asked to consider the issues-

What support and information do you need from agencies in Barnet to help  
You have more control over managing your long-term conditions?

How can a LINK work with health and social care agencies to improve this?

In discussion, the workshops also discussed a wider range of issues relating to the LINK and key factors in its success.

### Table 1

- expert patient scheme
- people put in touch with information they require
- information accessible and understandable for people with different languages and people with impairment
- being honest about condition and communicating clearly
- patients have to ask for information- should have been referred to specialist group/service
- doctor should have responsibility of putting you in contact
- internet- GP surgery link to sites
- families- outpatients
- patient information leaflet
- consultant gives specialist information
- diagnosis and recognising early
- patient with knee condition- operation cancelled three times then forgotten about

- kidney patient- had operation and dialysis – patient was not given information by doctor and consultant.

## LINKS

- look at good practice in other authorities where LINKS already set up to find out what works
- work together to create the organisation we want for the future
- local Groups need to know what each other are doing
- monitor the effectiveness of the LINK
- LINKS have involvement with health and social care- more input- more specialist input.
- links with Housing
- links involved with family/carer support
- get information from patients
- someone's got to collect- have power to write report- needs a reporting system.

### Table 2

- expert Patients
- GP as information giver – very important
- people have to be ready to hear bad news- might need a few opportunities to discuss
- download leaflets- by clinicians and experts
- family support as they are impacted by illness of one member
- carer involvement.

## LINKS

- LINKS can audit kind of information and process of giving information
- information choice- written; verbal; internet
- LINK is not only feedback- it should produce reports with recommendations
- scrutinise complaints
- benchmark with other performance elsewhere.

## Table 3

- expert patients
- easier and cheaper options for keeping fit including advice
- not enough information about expert patient programme
- need access to information in order to be an expert patient
- information and programmes on keeping fit and well.

## LINKS

- what are the mechanics of LINKS?
- communication: newsletter/e-mail/through existing groups
- spreading the word
- publicising sport/exercise that is available
- LINK should visit community centres.

## Table 4

- what is my role as lay person?
- commercialisation of NHS- how will this affect the LINK?
- complaints? Too many steps?
- helping NHS to deliver
- listening and changing
- but also look for positive
- so big? So how do you control? How does everyone get heard?
- how can I get involved with a LINK?
- role for host in developing communications strategy
- communities- small group area focus.

## Table 5

- what could a LINK do?
- people on LINKS understanding particular subjects so people can go to them- develop expertise
- can't overlook the fact people on LINKS are voluntary
- close engagement with Council and PCT (know main contacts and links)- is big issue at the moment
- take advantage of groups already there and link them up
- make demands to Council and PCT- but does LINK have teeth or is it just a tick box exercise?
- need to promote LINK in the community
- close links with BME groups and representatives on the LINKS- diversity of LINKS.

*'At first questioned my involvement as a hostel manager but saw benefit of being involved in this type of organisations we are already trying to make a difference to our clients'*

*'Hope we have more meetings to find out how LINKS and hosts will function'*

## Table 6

- aspergers (for adults) - lack of support and information not accessible in Barnet
- lack of choice in mental health services- how can this be addressed?
- patients doing the research
- moderate long-term care support?
- how trusts are providing care and support- acute needs
- how health professionals can understand better patients needs- communications?
- how do we move to a new patient/health provider relationship?
- element of trust to enable better dialogue/communications
- issues of cost/local issues/local groups organising themselves
- share good practice and get information to right people at right time advocacy
- value for money and question of resources.

## How will LINK work-key features:

- open
- inclusive
- dialogue
- information on health needs
- ensure all have a voice
- inspections won't work
- input into generic issues like expert patient programme
- broad health and social care remit
- involve organisations
- governance - who will be speaking for who?
- how will LINKS use local, established networks?
- will there be 'real' results, making a difference?

## Workshop Feedback and Reflections

### Barrie Taylor, Centre For Public Scrutiny Barnet LINKS Adviser

Barrie Taylor made some concluding remarks based on his experience of LINKS and from observing the workshops.

LINKS were an opportunity to widen interests across health and social care even though this meant accepting there would be another period of change in respect of health and social care being devolved to community level.

He identified that they needed to develop a positive reputation – and this would require work on relationships as a primary focus, even though individual issues were also important and would inform the development of a work programme, One of the initial relationships would be with the Overview & Scrutiny Committee. LINKS should also engage with the HealthCare Commission Annual Health Checks.

He also suggested that Barnet Council consider appointing a member to be a Champion for LINKS.

#### He highlighted some of the key issues and queries that had arisen in the workshop as:

- how to promote the Barnet LINK
- how the effectiveness of the LINK is monitored
- showing how the LINK had made a difference
- the role of the Host and being clear that the membership decides the best governance

model and the host is there to support that process

- the need for attention to be given to a communications plan (including the widest possible variety including forms, texts, virtual communications and use of all LINK members existing networks)
- engagement of youth by targeting their interests
- the needs of carers
- the need to ensure that LINKS had adequate powers, to avoid being a tick box exercise.

*'Extremely informative and I found people's experiences really interesting'*

## Concluding Remarks- Councillors Hart and Hillan

Councillors Hart and Hillan thanked all those attending and expressed the wish they would continue to be involved. Delegates were reminded of the importance of completing feedback sheets which asked them for their special interests and to confirm they were happy to share contact details. Everyone who attended or who had expressed an interest in LINKS would be sent a conference report.

## Feedback from delegates on the event

Did you find it useful?

Very useful	9	Fairly Useful	14	Slightly useful	5	Not at all useful	0
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What did you think of the content of the presentations and discussions?

	Excellent	Good	Fair	Poor
Jayne Taylor - LINKS	4	18	8	1
Commissioners and Providers - How we see the LINK helping us	4	17	8	1
Andrew Burnett - health and care needs - managing your own conditions	11	15	5	0
Workshop discussions - what support do you need	5	15	6	2

What did you think of the organisation of the event?

	Excellent	Good	Fair	Poor
Invitation and joining instructions	12	12	3	0
Access to building - parking, signage etc	5	13	6	5
Venue layout and acoustics	10	17	3	0
Catering	13	9	1	0