

Notes from the Cornwall LINK meeting – 22nd May 2008

Development of the LINK

What methods would you use to map the different and diverse groups, organisations, and individuals who may wish to engage with the LINK?

- First ask the question “why?” we need to find out the information - To find groups we need to engage with...

Possible groups/organisations:

- Volunteer bureaux
- Healthy Neighbourhood Projects
- CN4C
- Arts for Health
- Parish Councils
- Supporting People
- NHS Direct
- Support/self-help groups – both independent and involved with national organisations
- Libraries
- Voluntary Sector Forum
- Youth Parliament
- Cornwall Youth Partnership
- Large voluntary groups who will feed onto smaller satellite groups
- Disability Cornwall
- Health Promotion Service businesses

- We would find the groups through their reputation and effectiveness.
- We would contact the groups to collect their views and feed back results of conversations.

- But is it too early to contact all these groups/organisations? The LINK may need to show its strength before major publicity. There are one or two issues which could be taken forward now.

What creative ways would you use to reach out to communities, organisations and networks, to encourage them to engage with the LINK?

- The LINK must ensure it reaches people who work/have care commitments/young people/BME groups and so on.
- Film making
- Music
- DVDs/CDs to raise awareness
- Telephone calls
- Questionnaires
- Radio/TV – eg Penwith Age Concern network
- Hospital radio
- Local press

Suggest a model for the Cornwall Local Involvement Network...

The model could be a family tree with satellites (an extended family). But the family tree should be inverted to have the largest group of members at the top.

The LINK name – perhaps this could be personalised for Cornwall in the future.

Communication

What mechanisms are already in place that the LINK could use as methods of communication?

- Health professionals in the community – health visitors, district nurses, social workers etc.
- Word of mouth
- All newsletters
- Umbrella group websites (with links)
- Forums
- Police Diversity Officer/groups
- Charity shops (links with community)

- Internal communications for council and NHS staff
- Local press/ media
- Migrant workers / Link into Learning

What methods of communication should the LINK use to get information out there?

- Consider disabilities (access to venues, loops etc)
- There should be a clear co-ordination of information
- Create a big database
- Run small, regular accessible face to face network meetings (Access Cornwall)
- Ensure that all information is fair
- Link with groups and organise information events
- Leaflet drops in local paper – area specific
- Use District Council newsletters
- Flyer/posters in local halls, community centres, parish halls, post offices
- Supermarket noticeboards
- Schools – notes home with children
- Deliver to housebound with library books and meals (WRVS)
- Research information packs from a variety of organisations – eg tenant groups, social services clients, home care service users.
- Work with groups in health and social care
- Text messages
- Local radio

What kind of language should be used by the LINK?

- Kernow Positive Support
- Make pictorial information available
- Language used to be inclusive and friendly
- Publications and documents should be attractive and look good, with no jargon.
- Bullet points

- Communications experience must be part of the job description of the new officer
- Different formats
- Speak to CDA, Blind Association, for advice
- Use audio
- Hospital radio
- PLAIN ENGLISH / OTHER LANGUAGE
- Easy to read type face / font size
- Consider the colour of the background
- Short and sweet and concise
- Use case studies
- Website should be excellent (Google gold standard)
- Link with specialists – MENCAP, Blind Association, CDA

The Core Implementation Group

What is the preferred criteria we will be looking for in nominees?

- Willing to resign/ stand down when a new group is set up in September
- Nominations from groups?
- Geographical representatives
- Volunteers with skills
- Members who will be clear, concise and to the point
- Experience of health / disability needs should be incorporated
- Visionaries / finishers
- Need to identify strengths and weaknesses through meetings
- Create a database of skills and experience
- CVs / expressions of interest / biographies
- Knowledge of IT
- Legal and accounts experience

How many members?

Six – no more than 12.

The chair would have the casting vote.
Geographic representation and spread of interests.

How would the Core Implementation Group communicate?

- Through the Host
- E-mail
- Newsletter
- Intranet
- Mail

Code of conduct

What rules should the LINK adopt for the conduct of its open meeting?

- Respect for people's views – they must be given time to listen
- Induction
- Open and transparent discussions
- Clear process – eg explanations, procedures, clarity about how action and information will be taken forward
- Chair / facilitator will be given skills / training to enable meetings to remain focused.
- Offer a process for other meetings to put forward issues
- Meetings should be sufficiently resourced and accessible

What rules should guide the behaviour of members of the proposed implementation group?

- Look at existing models and standard rules (parish councils)
- Flexible rules
- Members should be problem-solving rather than putting up barriers
- Give a commitment to attend regularly
- Collective responsibility
- Leave personal agendas at home

- Media relationships
- Skills mix
- Is the representation from an individual or interest group?
- Ensure open to all, inclusive to all groups
- Confidentiality respected
- Induction
- Forward thinking

How should the LINK deal with conflicts of interest?

- Register conflicts of interest
- Nolan
- Establish principles of Nolan asap
- Induction and training, give information to implement
- Protocol for undeclared expressions of interest
- Take personal responsibility

Thoughts from the meeting

Sort out the differences between Social Care and care for health. The funding is different. See the illness ME/CFS with over 2000 patients in Cornwall. Nearly 700 are bed or housebound. 56% cannot wash or feed themselves at some point in the illness. 88% have been or are bed/housebound, 24% of bed/housebound have been ill so long they no longer see their GP.

So who is caring for all these people? As life management is the only real treatment for the illness, for the severely ill care is a medicine. Sufferers are also a danger to themselves and need to be watched over.

It has been proven that the earlier care goes in the greater the chance of reducing the impact and severity of the illness which, in turn, reduces further need for care and thus the cost of care. However, as Social Services are the providers of care and charge for their services, many cannot afford care.

Also, as they are having care for health reasons, they should be funded by the NHS, not Social Care.

So – Get sick people speedy care funded by the NHS, and it will cost the nation less money in the future.

Wendy Trebilcock MESH

More ideas and thoughts

- CWIC, Cornwall.gov.uk (network of the old Carers' Forum)
- Word of mouth
- The LINK needs a good, accessible website
- Meetings should be during the day and the evenings so as not to discriminate against those who work
- Mega database of names who can participate in debate or say views
- Take "Health Miles" into account – provide services where needed
- Use IT (video links) for "consultant" meetings to reduce travel where possible (eg regular check-up)
- pellerikerow@btinternet.com does the quarterly newsletter for MESH (ME self-help) Cornwall
- Publicity – GP surgeries / post offices / pubs
- Please could we have names and contact details of delegates here today – I would like to chat with a few people.
- Availability of transport
- Cost of petrol/diesel
- Friends of surgeries
- Don't forget Devon – many Cornish patients are treated in Barnstaple or Plymouth.
- Worried about the wide remit and the whole thing becoming a monster out of control with no teeth,
- Allow for chronic disease – people may be very interested in contributing but sometimes unable to do so eg chemotherapy

Ideas about the role of the implementation group

- Teleconferencing – anything to help those most isolated gain access to meetings. This is essential.

Jenny Pheby - Mental Health Project Manager