



Number 2: March 2000

The Bridge

Linking users, carers and staff in shaping health and social care services.

“Any number of commentators currently provide guidelines for encouraging meaningful user involvement at both the individual level and for groups, with strategies designed for workers to use with their particular client groups but also for managers to encourage appropriate representation and involvement at decision-making levels. But it is only by acknowledging the changes in practice which are implied by encouraging greater user involvement that the rhetoric of participation can become an active reality.”

Ross K 'Speaking in Tongues: Involving Users in Day Care Services' *British Journal of Social Work* 1995

Involving People with Learning Disabilities in Developing Services in Lincolnshire

Lincolnshire is actively encouraging people who use learning disability services to speak out for themselves. Annual conferences have been held and facilitated by Advocacy in Action. There have been two countywide conferences and three local ones in Boston, Grantham and Louth. Service users also organised some presentations for family carers, with the theme "What Speaking Up Means To Me".

As a result of feedback from the conferences, a group of people with learning disabilities, and their supporters, have been meeting for some months now.

They are working on a plan to support the continued involvement of people with learning disabilities in planning and decision making around services. They have already produced an "Ideas Document" for consultation and are currently making plans for a Roadshow. This Roadshow will give the group the opportunity to share and gather ideas from an even wider cross section of people with learning disabilities.

This work is still at an early stage, and is progressing at a pace dictated by the members of the group. This means that the work will have strong foundations, firmly rooted in the commitment of Social Services to provide responsive Learning Disability Services.

**Helen Dorr Acting User/Carer Partnership Manager
Lincolnshire Health Authority**

Overview of mental health service user involvement in the Holderness area

Rosedale Community and Acute Unit provides mental health services for this coastal and rural area of East Yorkshire. 60% of the population live in the 3 major population centres of Hornsea, Withernsea and Hedon, leaving 40% living in isolated villages and hamlets.

Rosedale is a purpose built unit situated on the outskirts of Hedon and provides both mental health and primary care services. This Unit has been operational since November 1996, providing a 24 hour mental health facility comprising in-patient care (7 places) and day treatment (4 places daily). The Unit also provides the Intensive Home Support Service which offers a high level of support for people in the acute phase of illness who are living in the community.

The Holderness Patient and Staff Involvement Group

Representatives from health, social services and voluntary/service user groups such as the Mental Health Action Group and MIND meet once a month to discuss and review local community mental health services. Most of our patient involvement activities were initiated from this group. Suggestions, concerns and information are shared in this forum. The written comments placed by day care service users, outpatients and staff in our suggestion box are discussed and action plans formulated.

Patient Support Group

This group meets weekly at Rosedale. The group encourages mutual support and exchange of experiences between patients. This group also arranges social outings and fund raising activities.

Mental Health Interest Group

This is a group for patients, carers and staff from across the health Trust. The group meets monthly and invites guest speakers to provide information on topics relevant to mental health.

Patient Liaison Surgery

At this weekly clinic past or present patients who are registered as volunteers interview service users and/or carers to talk about their options regarding the care they receive. An anonymous semi-structured questionnaire is used for these interviews, this hopes to encourage honest feedback whilst using services as well as following discharge. Volunteers meet with staff after the surgery to discuss immediate concerns. The questionnaires are collated every six months and presented to the team. This highlights positive aspects and development opportunities for the team. This service is currently not in operation as a new Patient Liaison Team is being recruited.

Welfare Rights Information Clinic

A patient runs a weekly clinic open to all service users giving information gained from his Disability Rights Advisory Service training. This is now a well established service providing both staff and patients with practical information and support in obtaining the correct benefits for patients.

Involving the wider community: The Horticultural Project

A piece of land has been identified for a therapeutic garden at Rosedale, and staff have worked hard to involve the local community, raise funds, and prepare the land for use. Many patients have volunteered and continue to give their time and commitment to this project.

Local Voice Meetings

This is a six monthly forum for all statutory and voluntary agencies involved in mental health and open for anyone in the locality to attend. Meetings are held at different venues across the locality. The aim is to discuss local issues, highlight gaps in services and share information about service developments. The meeting is co-ordinated by the Mental Health Action Group and guest speakers are often invited to attend.

Patient involvement in student training

This was initiated in conjunction with Hull University. Patients provide students with written feedback about their time on the unit. Students can ask for feedback they would find helpful for their professional development. This is an informal arrangement at present, although patient feedback is taken into consideration within the student assessment process.

For further information contact Vicky May, Unit Sister, on 01482 898202 at the Rosedale Community Unit, Preston Road, Hedon HU12 8JU

East Yorkshire Rural Stress Initiative

A project aimed at supporting farmers and farming families in rural communities who are experiencing distress.

Background: farming people are at high risk of stress for a number of reasons which include isolation, long working hours, living "on the job" for 365 days a year, increased bureaucracy, lack of control over factors such as the weather and farm prices and fear of falling incomes. They also have easy access to the means of taking their own lives. They are traditionally reluctant to access services and helping agencies.

In June 1998 several concerned agencies and individuals involved with rural communities in East Yorkshire decided to set up a project aimed at contributing to the reduction of the high suicide rate amongst the farming community and alleviate rural stress in general. Health Action Zone funding has been earmarked for a 2½ year project managed by a multi-agency steering group. It will be similar to other rural stress initiatives in other parts of the UK but tailored particularly to the needs of the East Riding of Yorkshire.

Project aims:

- To train a group of rural links (people who have some kind of business in the rural community such as seed merchants, agricultural representatives etc). They will give information and details of helping agencies to those in rural communities and encourage them to ask for help.
- To develop a rural information campaign aimed at rural communities to raise awareness of helping agencies e.g. Samaritans, Citizens Advice Bureau, Farm Crisis Network, MIND etc.
- To develop a media campaign which helps to change the culture of suffering in silence amongst people in rural communities, especially farmers, by removing the stigma of asking for help.

Partnership agencies include: Hull & East Yorkshire Community Health Trust, Yorkshire Agricultural Society, Hull & East Yorkshire MIND, Samaritans, Citizens Advice Bureaux, Country Landowners Association, Yorkshire Rural Community Council, Agricultural Colleges, Churches, Farming and Rural Conservation Agency, National Farmers Union.

For more information contact Cally Barker, Rural Stress Co-ordinator at Cally@eyhealthprom.karoo.co.uk, telephone 01482 886626 or Health Promotion Department, Archway Offices, Westwood Hospital, Beverley HU17 8BU

User Charter and Monitoring Project in North Lincolnshire

We have started a mental health user charter project, following the example of East Riding's excellent work. We wanted to develop user monitoring and quickly realised that users had to set the standards if they were going to monitor them. The User Group Project, which is supported by MIND, is taking the lead, supported by Social Services. The project has the blessing of the local mental health Partnership Action Team. It's early days but we have some keen users and staff involved and Laurie Bryant from the East Riding Monitoring Project is helping to get the project going.

We will keep you informed as it develops.

Public consultation and user involvement

"the processes by which services learn from those they serve".¹

User involvement might be defined as inclusion of service users in the planning and management of services, while public consultation is "a local attempt to seek the views of a broad constituency of persons"² who are not necessarily current service users. If services are to be needs-led, then it is the wider community who need to be involved, to identify unmet need in marginalised groups and people who do not use services.

¹ Polley S 1995 Druglink

²Harrison S & Mort M 'Which Champions, Which people? Public and User Involvement in Health Care as a Technology of Legitimation' Social Policy and Administration vol 32 no 1 March 1998 p60-70

People might be involved in a range of ways, as:

- Individuals taking part in an assessment process or treatment decision
- Individuals contributing their own views and experiences
- Individuals reflecting the organised voice of a group with a particular interest in common

Contributing to:

- the strategic framework or vision for services
- identifying and prioritising needs and allocating resources
- planning and purchasing services
- developing assessments and providing services and packages of care and support
- monitoring, reviewing and evaluating services and taking part in inspections
- staff selection, training and development

There are different levels of involvement, and it is important to recognise the level you are working at:

- Giving information
- Consulting
- Deciding together
- Acting together
- Supporting independent community interests

There are two ways of looking at these levels

1. They could describe a process where people develop their power and responsibilities through being involved
2. Or, they could describe the level of participation that is appropriate for a particular purpose. For example, if you were following a legal requirement where there was no possibility of negotiation, it would be appropriate just to give information.

Giving information

Good quality, appropriate, accessible information underpins all user involvement.

Just giving information isn't involving people, but it people do need information to get more involved, so it might be the first step. Giving information alone is a one way process that suggests that there are 'experts' who know what the options are, and that there aren't any alternatives. Information that helps people to make choices about their own care or treatment can be improved by asking service users to identify what it is that people want to know, and then helping to write it in a way that others will understand.

Consultation

Allows choice between a limited number of options that have already been decided on. There is no opportunity to propose alternatives or take part in putting plans into action. Service users do not have the opportunity to contribute to the agenda or express their own priorities. Community Care Plans usually go out for 'consultation'. Research 6 years ago showed that 88% of them were circulated in draft form before there was any input from service users.

Deciding Together

There is negotiation that includes all the different interests, so that priorities and a course of action are agreed jointly. There may be boundaries, such as financial limits, but everyone's view carries equal weight.

Acting Together

Working with others to find solutions and carry through the action agreed. Implementation of decisions requires co-operation, and this means building trust and ensuring a more equal balance of power and resources between the different partners.

Supporting local initiatives

Supporting independent groups to develop and implement their own solutions, which means delegation of power and resources to user and voluntary groups.

(Based on: David Wilcox 1994 Participation Guide Partnership Books Brighton Available online at www.partnerships.org.uk)

Workshop News

As a way of sharing skills and ideas and turning theory into practice we are holding a series of workshops open to all those with an interest in 'user involvement'.

Advocacy- a way of including those whose voices aren't heard?

March 24th, with Joe Monaghan, National Development Worker, Citizen Advocacy Information and Training. This day will be featured in the May edition of The Bridge

Involving older people May 12th, Kingsway Centre, Scunthorpe.

Applications invited from all those who work with older people, including those working in housing and residential care and primary care.

Involving people with dementia September 28th, Education Centre, Coronation Road North, Hull, with David Sheard. David has worked as an Associate Consultant with the Dementia Services Development Centre and is a Training Consultant with the Alzheimer's Society. He has experience of working in both health and social services

So this is the second edition of The Bridge. What do you think of it so far? Do you find it interesting and useful? We know that there is an awful lot going on that could be shared in this newsletter, and more we could add, such as

- **a letters page,**
- **contacts and phone numbers**
- **more articles and information**

So tell us what you want to see, and tell us how you are involving people who use the services you provide to include in the May edition.

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