



Number 3: May 2000

# The Bridge

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

**“It is often the most isolated and the least identifiable of users – the ones who are never heard- who have the sorts of experience which can be most valuable”**

**Averil Osborn Age Concern Scotland**

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

Joe Monaghan, National Development Worker for Citizen Advocacy Information and Advice, recently led a workshop on advocacy.

Joe described different types of advocacy and the range of activities advocates might be involved in. Local illustrations of 'advocacy in action' were provided by the Hull & East Yorkshire Advocacy Forum; Mencap; Liesel Dickinson, Independent Living Scheme Co-ordinator, Choices & Rights Disability Coalition; and Humphrey Forrest of the Humberside Law Centre. Discussions included **'who can benefit from advocacy?'** **'what is good or successful advocacy?'** and **'conflicts of interest and cultural sensitivity'**.

User involvement might be defined as inclusion of people who use services in the planning and management of those services, as well as in personal decisions about their care and treatment.

## **What is advocacy?**

*Speaking up - on behalf of yourself or others. Saying for someone else what they would want to say for themselves.*

**'Advocacy is when an individual or more than one person have their views put forward by someone else (acting as an advocate). Sometimes we cannot put our own views and wishes forward for a variety of reasons, we may lack confidence or may not know exactly how to go about making our voice heard. It may be that we know how to say what we want, but are not listened to. Advocacy is about protecting and enhancing peoples' rights and ensuring that they have a voice in the decisions that affect their lives.'**

From: Liverpool Community Advocacy Development Project leaflet

## **Why Advocacy?**

We all need support when facing problems or difficult choices. Most of us will have a network of friends and contacts to call upon. Some people are cut off from wider communities, or may experience the isolation that can accompany ageing or difficulties with health or personal security. Such people may have their views, wishes and rights ignored. Advocates can provide practical and emotional support and representation to make sure that people are not discriminated against.

Many reports have suggested that people who use health and social care services should have access to an independent person who can support them to speak up for themselves, or speak on their behalf. People with an interest in involving service users are concerned to include vulnerable and marginalised people. Advocacy has the potential to include those whose voices would not otherwise be heard.

*"If ..advocacy were to be recognised as a means of empowering users (by advocates accompanying them to meetings), then many more of them would have a physical presence at formal events, rather than having their views represented by someone else while they stay at home."*

From: User involvement- Giving Older People a Voice Susan Thompson

## **Advocacy is about:**

**Empowerment** of people, where possible to be their own advocates.

'We aim to empower people to sort out their own problems for themselves, and realise their own potential as citizens with the rights and responsibilities that entails.'

**Autonomy and self-determination.** 'Advocacy enables people to be more in control of their own lives, by having information, support to make their views known and greater involvement in decisions'.

**Citizenship** Safeguarding rights, and working towards 'A way of promoting equality in practice'.

**Inclusion** of otherwise marginalised people.

From: Atkinson D 1999 [Advocacy – A Review](#) Research Into Practice series Joseph Rowntree Foundation Pavillion Brighton

## **Who could benefit from advocacy?**

people who are:

- physically or socially isolated
- vulnerable
- powerless
- discriminated against or devalued by society`
- dependent on others, such as carers, service providers
- unable to communicate conventionally
- need help to understand information
- need support to represent their interests
- find difficulty in being assertive
- those who need safeguard against abuse
- all of us, in certain circumstances

## **advocates can help service users with:**

- having confidence to speak on their own behalf
- finding and understanding information
- expressing choice and preference
- weighing up options and making personal decisions
- at periods of transition
- obtaining social, health and leisure services, and welfare benefits
- support at community care assessments, reviews, case conferences, doctors appointments
- challenging stereotypes and defending cultural identity
- links into the wider community
- taking part in groups, meetings, committees
- conflicts with family/carer
- appeals and complaints procedures

## **Some examples of advocacy**

Two independent advocates from a voluntary organisation spend half a day a week in a residential home with residents with dementia. The aim is to promote and protect residents' rights, and ensure their views and comments are heard. No additional funding was used to set up the project. Feedback from the advocates has led to practice and policy developments.

From: Community Care 18-24 November 1999

Sue, a woman with learning difficulties wanted to move out of her mother's house, where she lived with her own daughter. She asked her advocate to help her work out the best way of helping her to get a place of her own. The situation was complicated, because grandmother had responsibility for grand-daughter. The advocate accompanied Sue to her solicitor's to check out her legal rights, to an advice centre to find out about her benefit entitlements, and to the housing office to see if there might be any suitable tenancies near to her mum's. Together they made a list of everything that Sue would need to furnish a house.

Armed with all this information, Sue used her advocate to rehearse the pros and cons of moving. In the end she decided to stay where she was for the time being and save money for when she was ready to set up on her own.

From: Booth W & Booth T 1998 Advocacy for Parents with Learning Difficulties: Developing advocacy support Joseph Rowntree Research into Practice series Pavillion Brighton

### Some useful websites:

Participation guide [www.partnerships.org.uk](http://www.partnerships.org.uk)

Public Involvement Programme [www.pip.org.uk](http://www.pip.org.uk)

Consumers In NHS Research Support Unit [www.hft.org/ConsumersinNHSResearch](http://www.hft.org/ConsumersinNHSResearch)

Citizen Advocacy Information and Training [www.leevalley.co.uk/cait/](http://www.leevalley.co.uk/cait/)

Leeds Advocacy [www.leedsadvocacy.org.uk](http://www.leedsadvocacy.org.uk)

NHS Primary Care Groups Public Engagement Toolkit  
[www.doh.gov.uk/nyro/pubtool.htm](http://www.doh.gov.uk/nyro/pubtool.htm)

Listen up! Effective community consultation  
[www.audit-commission.gov.uk/ac2/NR/LocalA/breffect.htm](http://www.audit-commission.gov.uk/ac2/NR/LocalA/breffect.htm)

## **Beverley and Hessle Local Working Group *Some Reflections***

One of the objectives of the Local Working Groups was to 'actively involve user and carer representatives in the process of needs assessment, service planning, evaluation of services and specific issues'.

From the outset the Beverley and Hessle Local Working Group took its responsibilities seriously with regard to consultation. Its first attempts were to consult with specific client groups such as older people, and some very useful information was provided by these early meetings.

However, as with all things, this way of gathering information with regard to need became less effective over time and it was agreed to try something different. A Local Working Group Roadshow took to the area with a series of public meetings. These again produced interesting results, but attracted disappointingly few people. Indeed the Local Working Group was beginning to question how consultation could be made more meaningful, and decided last year to invite responses via an anonymous questionnaire. This in fact did produce a more widespread response but involved some of the member of the Group, particularly the Chair, in some considerable amount of work.

To conclude, I feel our consultations have been useful with regard to informing service provision and we have tried a variety of methods to include the views of people who use services and of carers. In the future it would be nice to be able to feed back to people along the lines of 'you said this, and this is what happened', otherwise it seems like people get consulted ad infinitum with no identifiable results.

Sue Colman Chair of Beverley and Hessle Local Working Group  
(*These are Sue's own reflections, and not the views of the Group as a whole.*)

## ***An experience of Participatory Appraisal***

In response to the challenge of tackling health inequalities, East Riding Health Authority commissioned the Health Promotion Service of Hull & East Riding Community Health NHS Trust, to undertake a review of the range and types of health promotion interventions which are happening in the twenty-one most deprived electoral wards in the area. In addition the review aimed to gather a community perspective on health.

In my previous post as Community Health Development Worker I had worked in communities where external researchers or consultants were commissioned to conduct research. The memory was still fresh of the community response to these 'outsiders' which was "*Why do they always pay outsiders to say what we could have told you, we are the experts... they wouldn't pay us to do it*" or "*It's just another case of professionals gathering qualifications or building their careers on our backs*".

A method was developed to build on skills already developed in the community. Local co-ordinators arranged research sessions within their community using selective elements of participatory appraisal methodology.

Co-ordinators and session workers were drawn from The Hull & East Riding Participatory Appraisal Network. This Network has developed a pool of local people who have been trained in Participatory Appraisal methods, familiar with the use of highly visual tools and techniques and knowledgeable about the local community. In most cases the co-ordinators either lived or worked within the community being researched.

A report was produced by the co-ordinators for each of the electoral wards reflecting community responses to four questions:

- What does being healthy mean to you?
- What affects your health (good and bad)?
- How has this community changed in the last five years?
- What do you think local people could do to improve health in this community?  
What could others do to improve health in this community?

These community appraisals have therefore been carried out with a community development philosophy building on skills within the community. The resulting reports provide a varied and vivid picture of life in these communities. Many responses reflecting local and current issues at the time of the research. The contact rate within each ward varied. Session workers made contact with people through community groups, in shopping precincts or just on the streets thus contacting a varied age range of both males and females. Over 2000 people have taken part in this process which is one part of a larger review of health inequalities and health promotion to be published at the end of May, 2000<sup>1</sup>.

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<sup>1</sup> Health Inequalities and Health Promotion in the Kingston upon Hull and the East Riding of Yorkshire, Health Promotion,

Participatory appraisal is increasingly used both as a research strategy and as an educational process, particularly in the Hull and East Riding area. There will continue to be debates about power relationships between researchers and respondents and the importance of the qualities, skills and attitudes required from practitioners<sup>2</sup>. This innovative methodology has provided an opportunity to test a method, which involves local people as researchers leaving as much control as possible to those who have been appointed co-ordinators. There is no doubt this will give rise to a debate about validity, reliability and generalisability. Lessons will be learned from this methodology to inform future practice.

From my point of view this research has been an exciting challenge, particularly in overcoming what at first seemed a very negative, sceptical point of view from both community and professional researchers. At times it felt everyone was a critic and yet towards the end many seemed quite keen to be involved. I have had to overcome many practical problems created by the attempt to merge organisational cultures with those of the community, gaining ethical approval, and in some cases the unequal spread of skills within the communities being researched. The analysis of 21 different reports, which vary greatly both in length and content, was both challenging and time consuming.

Following publication of the research report there will be an evaluation of the methodology used for the community appraisal. Hopefully this will provide a measure of the extent the research process has contributed to community capacity development.

Jo Stott Senior Health Promotion Specialist Hull & East Riding Community Health

**North East Lincolnshire Disability Coalition** in conjunction with  
**The Humberside Law Centre**  
**Choices**  
Conference for People with Disabilities  
  
at **Immingham Resource Centre**  
Margaret Street, Immingham, NE Lincolnshire  
Friday 30th June 2000

The conference aims to highlight choices, opportunities and services available to disabled people in the North East Lincolnshire area. A selection of workshop sessions will be on offer throughout the day, covering issues concerning Independent Living, Direct payments, Disability and Housing, Human Rights and Disability etc. Our guest speaker will be a member of the Disability Rights Commission. For further information or reservations please contact the **North East Lincolnshire Disability Coalition** on **01472 234222**.

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<sup>2</sup> DeKoning, Korrie & Martin, Marion *Participatory Research in Health: Issues and Experiences* Redwood (Trowbridge 1996)



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'.

Involving people with dementia **September 28<sup>th</sup>**. Contact your training department for details.

Involving Older People **July 10<sup>th</sup>**. This workshop is **open to anyone who works with older people** -in hospitals and primary care teams, social work teams, homecare, day care, , residential and nursing homes, wardens, voluntary groups. A certificate of attendance will be given. Application form on back page.

**Programme -'involving older people' workshop 10<sup>th</sup> July 2000  
Kingsway Centre, Scunthorpe ( Bridge-side outskirts)**

- 9.00 coffee, registration, display and quiz
- 9.30 Chair's introduction
- 9.35 **Why** involving older people is important - Mike Briggs Adult Services Manager North Lincolnshire Social and Housing services
- 9.50 **What** does 'user involvement' mean?- quiz answers
- 10.00 **How** do we involve older people in shaping services?-an example of practice
- 10.30 **coffee**
- 10.50 groupwork & feedback
- 11.50 Barriers to involving older people
- 12.10 Involving people in nursing and residential homes -a Lay Inspector's view Peter Lounds
- 12.30 **lunch** -and challenge
- 1.30 challenge feedback - identifying barriers to participation
- 1.45 Getting involved in the community  
Jean Wormwell, member of National Service Framework for Older People Reference Group, and members of Bridlington Pensioners Action Group
- 2.15 groupwork and feedback (**tea** 2.45)
- 3.15 **How** do we involve older people in shaping services-an example of practice
- 3.45 Chair's summary  
Where do we go from here - Developing an ' involving older people' network?

**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, so tell us what you want to see. How are you involving people who use the services you provide ? Voluntary organisations- 850 copies of The Bridge are distributed to voluntary groups and health and social care workers. What are your views and experiences of consultation?**

Please send items for the September edition of The Bridge, preferably on disc or e-mail, by **August 15<sup>th</sup>**. **OR**

**get in touch with:**

**Gil Everett, CCNAP, Health Place, Wrawby Road, Brigg DN20 8GS**

**Tel: 01652 601110; email [gillian.everett@shumber-ha.trent.nhs.uk](mailto:gillian.everett@shumber-ha.trent.nhs.uk) or**

**Alan New, The Angel, Market Place, Brigg Tel: 01724 296489**

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Application for place at 'Involving Older People' workshop  
**Monday 10<sup>th</sup> July 2000**

Name:

Address & contact tel. No:

What is your job?

Please outline what is being done or planned in your workplace or service area to involve the people who use the service

Send to: Gil Everett CCNAP, Health Place, Wrawby Road, Brigg DN20 8GS by **Monday 19<sup>th</sup> June**

Map and final details will be sent two weeks before the day.