CHC NEWS

A newsletter for community health council members and staff

Around the party conferences

Frank Dobson must have been greatly relieved that the "super-tanker" of NHS waiting lists started to turn before he was due to address the Labour Party conference. He took the opportunity to release the latest set of monthly statistics, showing that lists had fallen by another 20,000 in August. He announced a further allocation of £320 m from the NHS Modernisation Fund to tackle waiting lists and waiting times. Mr Dobson went on to question the wisdom of the severe cuts in NHS bed numbers – down by 100,000 over the past 10 years. He announced a national inquiry into how many beds are needed, what type they should be and how they can be best used.

The health secretary went out of his way to praise NHS staff, re-iterating steps he has taken to try and improve their conditions of work. He stopped short, however, of promising not to stage their pay awards, instead challenging the pay review bodies to come up with recommendations that are "affordable to the NHS".

For Mr Dobson's announcement of joint guidance to the NHS and social services, see page 2.

Guardian 1 October; www.conf.labour.org.uk

Anne Widdecombe's speech to the Conservative Party conference went down well with delegates, partly, no doubt, because much of it was spent deriding Labour's performance and partly because she went further than the Tories have done before in proposing partnerships between the NHS and the private sector. She is, she said, committed to services free of charge at the point of delivery and to increasing health spending year on year, but she also wanted to find "imaginative" ways of funding health care innovations alongside "the essential core functions" of the NHS. "If we accept that our Health Service cannot do it all, then we must either resign ourselves to ever increasing rationing ... or look to increase the flows of additional new cash ... though common-sense co-operation with the private sector." Quite how this would raise cash is not clear and Miss Widdecombe was not offering any "prescriptive policies". Rather, she called on delegates to reject Labour's "facile debate" and to embark on the "mature debate" she wanted to initiate.

Times 7 October; www.conservativeparty.org.uk

The Liberal Democrat conference backed calls from Simon Hughes for a "national curriculum" of core services to be offered by the NHS. Mr Hughes argued that the "politically unacceptable" topic of rationing should be brought into the open, with professionals, patients and politicians drawing up "the menu of what health services we get for our tax pound". Of course, this raises the unwelcome prospect of going to the electorate with a list of treatments that would not be available, so the conference also voted to increase health spending. There were calls for a debate about the provision of "non-core" services. Delegates backed a proposal to give health and social services committees the power to raise cash for these services through council tax. Another suggestion was that patients could access non-core services through the NHS, but pay for them by "tapered contributions" – i.e. be means-tested.

Health Service Journal 1 October

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In this issue:

ASSOCIATION OF COMMUNITY HEALTH COUNCILS FOR ENGLAND & WALES
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Bridging the care gap

In a move to revitalise efforts to bridge the gap between health and social services, the government has published joint guidance for the two sectors on national priorities for the next three years. There is a strong emphasis on tackling the root causes of ill health and on joint planning and working. Specific targets have been set in 10 priority service areas. Some of the funding will be linked to plans and the achievement of the targets.

The 10 priority areas have been divided into three groups according to which organisation should take the lead, though both are expected to contribute to developments in all the service areas.

Social Services Lead	Shared Lead	NHS Lead
Children's welfare	Cutting health inequalities	Waiting lists/times
Regulation	Mental health	Primary care
Inter-agency working (especially in relation to children)	Promoting independence	Coronary heart disease Cancer

Despite the efforts to bring about inter-agency working in recent years, there are still barriers to the process. Some of these can be overcome by local efforts, e.g. wide involvement in drawing up Health Improvement Programmes. However, there are also legal constraints. The government has issued proposals to remove these constraints in a discussion document, *Partnership In Action*. It proposes legal changes to enable:

- pooled health and social budgets for specific service areas
- lead commissioning, including the ability to delegate functions and transfer funds between health and social services
- integrated provision in which the NHS can provide social care services or social services provide some community health services.

Attempts to provide a genuinely seamless service to users must be welcome, but some welfare agencies have raised concerns about the implications for charging users. The government insists that its proposals will have no effect on which services attract a charge and that the charging policy would have to be made clear to users. However, it has been questioned whether the distinction between free NHS care and means-tested social care could be sustained if one group of staff were delivering both types of care. Concerns about confidentiality are also likely to arise as there will be increasing pressure on agencies to share information about service users.

Guardian 17 September and DoH documents (below)

Modernising health and social services: national priorities guidance 1999/00–2001/02
Copies: phone 0800 555777; www.open.gov.uk/doh/coinh.htm

Partnership in Action: new opportunities for joint working between health and social services
Copies: phone 0541-555455; www.open.gov.uk/doh/pia.htm

Threat to PFI

New accounting guidelines, to come into effect from 1 January 1999, could undermine one of the main justifications for the Private Finance Initiative, putting the whole scheme at risk.

A ruling from the Accounting Standards Board (ASB), which regulates the private sector, has made it more likely that property assets and liabilities involved in PFI schemes will appear on the public sector balance sheet and not be transferred to a private investor. This is supposed to reflect the "economic reality" that hospitals built under PFI belong to the public sector. Under the guidelines, therefore, spending on PFI projects would count against the public debt – the very situation which PFI was supposed to overcome.

The head of "PFI Watch" at the Institute of Health Services Management has commented that, in this case, "you might as well build a new hospital with public money". The ASB, however, argues that PFI could still be the best option, since it might be cheaper to build a hospital under PFI regardless of the accounting arrangements. The treasury has denied that the ruling will have a great impact, saying that a private contractor's ownership of the assets would continue to be recognised in most cases. The government has decided that the guidelines will not apply to schemes which have already reached the "best and final offer" stage.

Health Service Journal 17 September

Wanting to see the dentist

There was a time when the sight of 1000 people queuing in the rain might not have been that surprising ... somewhere in Eastern Europe, of course – surely not in Britain. But that was the sight that greeted Dr Neil Corbett when he turned up for his first day of work as an NHS dentist in Truro. One couple was even making a 170 mile round trip in the hope of registering. Cornwall Health Authority says that there are 151 dentists in the county. Just 17 of them will register children for NHS treatment and 7 will register adults.

Daily Telegraph 17 September

Ambulance Services

In a report warning of the increasing pressures on ambulance services, the Audit Commission has recommended a reconsideration of the strict requirements for responses to 999 calls. Given the views of ambulance staff that some calls could be handled in different ways (see graph), the report suggests "tailoring" responses to meet individual circumstances.

The different responses envisaged in the report are:

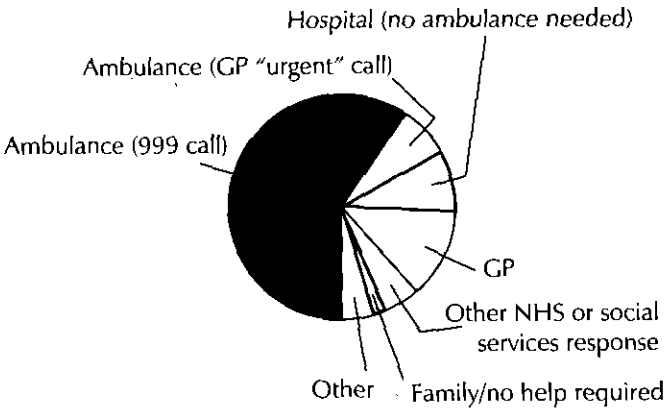
- relaxing the requirement for 95% of calls to be reached within a target time
- referring selected calls to another agency
- sending only one member of ambulance staff to some calls
- sending transport but not a fully equipped ambulance to some calls
- dealing with some emergencies at the patient's home, without hospitalisation.

In its response to the consultation document on the report, ACHCEW opposed any lowering of response time standards, commenting:

> " ... we believe the solution to inappropriate calls should lie in developing alternative services and in increasing the public's awareness of the range of services and advice which are available, not in denying people services which they believe they need or trying to make them feel guilty about accessing NHS care."

Ambulance crews' views of who should deal with calls

Source: London Ambulance Service survey of 2705 calls attended, reported in Audit Commission report



ACHCEW was concerned that some health authorities have contracted for a lower standard response time than the national target. The Audit Commission report recommends that "health authorities should take such a decision only after public consultation (including with CHC and GP representatives)".

There may be local pockets where response times are consistently poor, even though an ambulance service is achieving the aggregate target response times. The report advises health authorities to find out from CHCs (among others) whether such pockets exist locally. ACHCEW believes such information should be released routinely and distributed to CHCs.

A life in the fast lane:
value for money in emergency ambulance services
Audit Commission, 0800 502030, £20

RNIB Publications

A key principle of the Disability Discrimination Act is that service providers must make "reasonable adjustments" which remove barriers to disabled people. The government has announced that further duties to make "reasonable adjustments" will be implemented in October 1999. These two publications from the Royal National Institute for the Blind will be of use to organisations which are trying to identify how to meet the needs of blind and partially sighted people.

Within reason

Access to services for blind and partially sighted people

This Campaign Report alerts service providers to the views held by visually impaired people about some key services and their interpretation of what would constitute reasonable demands on service providers. A section on health includes a list of "high priority actions", e.g. providing dosage information in appropriate formats and enabling appointments to be booked and changed over the phone.

Putting vision into community care

This report results from a two-year analysis of over 200 community/social care plans for England and Wales. Aimed at both planners and those delivering services, it gives advice on the planning process. In doing so, it aims to raise the profile of visually impaired people and their needs. It includes advice on specific service areas and checklists.

Each report costs £5 from RNIB, 224 Great Portland Street, London W1N 6AA, 0345 02 31 53.

PCGs: Implications For People With Learning Disabilities

Roslyn Band, Policy Officer,
Mencap Campaigns Department

By 31 October, health authorities should have fixed the membership of primary care boards. GPs and nurses have had their say. What about patient interests?

Of course, all board members, not just the lay member, should understand the needs of their community. This is where CHCs and the voluntary sector have an important role, both investigating need and facilitating consultation with the people who use services.

So what would Mencap like primary care groups (PCGs) to understand about health care and people with learning disabilities? Here are the key facts arising from *The NHS – health for all?*, a recent report by Mencap of research into the health care experiences of nearly 3000 people with learning disabilities and 1500 carers.

> 70% of people with learning disabilities visit their GP four or fewer times a year. The average for the general population is five times a year.

Health problems may go untreated and yet regular health checks for people with learning disability, as recommended in 1995 Department of Health guidance, have yet to be set up widely. This year's guidance, *Signposts for Success*, spells out expectations more clearly, and the onus is on PCGs to put them into action.

People with learning disabilities need to be able to access general health services. They need information about services that they understand. They need services that can understand them – how to communicate, how to work in a way that establishes confidence and accommodates the extra time they may need. They need accessible health promotion information, especially on healthy eating, in the light of the high incidence of obesity among people with learning disabilities.

Further findings indicate other tasks for PCGs:

> Only 27% of the people in the survey had ever had their hearing tested ... yet the incidence of hearing impairment among people with a learning disability is reported as 37%.

> 53% of people with learning disabilities have not had a sight test in the last two years ... yet people with learning disabilities are known to be more likely to have sight problems than the general population.

> 72% of children with learning disabilities have had a dental check in the last year ... this compares to 96% of children in the general population.

Of serious concern is the low uptake of cancer screening services by women with learning disabilities.

> Breast examination averaged 50%, compared to an uptake figure of 76% for women in the UK; 8% had had a cervical smear compared to 76% of women in the general population.

Women with learning disabilities are deterred by a lack of information and sometimes misinformation – that such tests are something they don't need to worry about. Recall letters in "jargonese" may not mean anything to them, and fear of the procedure itself cannot always be allayed by staff working to a tight schedule. Initial resistance may be taken as refusal to consent, when several visits may be needed to build confidence.

At this stage, PCGs hold the promise of the new, without the disappointment of the known. One thing is clear – they will have more say over the services their communities need and that is encouraging. But before they speak – we hope that they are listening.

Spinal Cord Injury: A Charter for Support

Since specialist spinal injuries centres were introduced after the Second World War, there has been a dramatic increase in the life expectancy of people with spinal cord injuries (SCIs). It is estimated that there may now be as many as 40,000 people in the UK living with SCI. However, the Spinal Injuries Association believes that the system of care is under threat, partly because many health care professionals assume that patients with suspected spinal cord injuries can be adequately treated in general hospitals. The Association has, accordingly, issued a Charter for Support, setting out recommendations for treatment in four stages from acute care to long-term welfare. It recommends that all patients with suspected SCI should be referred to a specialist unit and that people with SCI should subsequently have access to the unit without a GP referral. The Charter also sets out brief guidelines for good practice in specialist units and the community.

The Spinal Injuries Association points out that some CHCs have been using the Charter as a guide when they have been evaluating local services.

Spinal Injuries Association
76 St James's Lane, London N10 4DF
Phone: 0181 444 2121, Fax: 0181 444 3761
Web site: http://jgrweb.com/sia/

UK Acquired Brain Injury Forum

This new forum has been set up to promote the interests of brain injured people, their families and their carers. Its main activities will be research, debate, identifying priorities and developing strategies for reform. It hopes to draw its membership from:

- individuals who have sustained a brain injury, carers etc. (membership fee £3)
- professionals (membership fee £10)
- organisations (membership fee £25)

The first AGM of the forum will take place in London on **28 November 1998**.

UK Acquired Brain Injury Forum
c/o Headway National Head Injuries Association
4 King Edward Court, King Edward Street,
Nottingham NG1 1EW
Phone: 0115 924 0800

There is a growing body of evidence to show that many people are living with unnecessary pain. The Patients Association has launched a campaign, **Action on Pain**, which aims to get across the messages that:

- the pain many people suffer can be managed more effectively
- chronic pain has a major social and economic impact
- pain management requires resources.

The Association has set up a PainLine, a phone number for people who want to give or receive information.

Callers in chronic pain will be offered a free booklet *About Dealing with Chronic Pain* and will be given details of their nearest pain management clinic.

PainLine will also be used to gather information on callers' experience of chronic pain. The resulting information will be used (along with other research results) in a report which will be published later this year. The intention is to generate as much media interest as possible so that the campaign grabs the government's attention. For this reason, the campaign would like to hear from people who would be willing to speak to the media about their personal experience.

To give or receive information, phone PainLine on: 0116 269 5568, 11 a.m. – 4 p.m.

Making partnerships work: towards best practice in partnerships between the pharmaceutical industry and voluntary health organisations
Available from: Dr John Spooner, Arbrook Associates, 8 Beaconsfield Road, Claygate, Surrey KT10 0PW; phone/fax: 01372 470879

It is quite an achievement to have persuaded representatives of 20 voluntary organisations and 13 pharmaceutical companies to spend a day exchanging views. This report draws on the discussions of a seminar sponsored by Pharmaceutical Partners UK. It sets out the principles identified as essential for a partnership – equity, transparency and mutual trust – and some ideas of how partnerships can work in practice.

Informing patients: an assessment of the quality of patient information materials
King's Fund
11–13 Cavendish Square, London W1M 0AN
Phone: 0171 307 2591

> **"... in many cases patients were being provided with inaccurate, misleading or biased information"**

There is a way to go before patients can be sure of receiving the information they need to understand their medical conditions and to make informed treatment decisions if they want to do so. This substantial study reveals a long list of shortcomings, including concerns about accuracy and coverage.

The research involved specialists and patients reviewing patient information materials (54 leaflets, videos and audiotapes) on ten medical conditions. Both groups gave comments and ratings. The specialists judged the materials rather more harshly than the patients, and they were more critical of the content than they were of the presentation. The patients were critical of the patronising tone of some materials and of insufficient coverage.

The authors have drawn up useful guidelines on the process of preparing patient information materials and their content. These include suggestions which might easily be overlooked. For example, it is recommended that information on *all* treatment options is included, even where an option is not recommended: it is better to mention an option and be explicit about evidence (or lack of evidence) on its efficacy than to be silent about an option which patients may have heard about from elsewhere. The guidelines point out that decisions about content should start from the questions patients want answers to. To help in this, it gives a list of 22 commonly asked questions.

As well as helping people who want to produce patient information materials, the research report would help CHCs and others who want to point enquirers towards good information on the medical conditions considered:

Back pain	Cataract
Depression	Glue ear
High cholesterol	Hip replacement
Infertility	Menorrhagia
Prostate enlargement	Stroke

Accrediting patient information

A system for ensuring that patients can get good quality information is on the horizon. The Centre for Health Information Quality (CHiQ), set up last year, is to develop QUIP (QUality Information for Patients), a database containing details of print and non-print materials tested for various aspects of quality. These will include readability, the evidence base and the involvement of patients and their carers in developing materials.

CHiQ has already embarked on work to improve patient information materials by promoting good practice and providing various forms of support to those involved in developing patient information. It consults a wide range of organisations through its Reference Group, on which ACHCEW is represented.

The Centre produces a number of publications which may be of interest to CHCs including a quarterly newsletter, *Hi Quality Matters*, and topic bulletins. To receive copies, contact the Centre at the address below.

Centre for Health Information Quality
Highcroft, Romsey Road, Winchester SO22 5DH
Tel: 01962 863511 ext. 200, Fax: 01962 849079
Website: http://www.centreforhiq.demon.co.uk

Information for Health

Improving patient information is an important aspect of a new Information Strategy announced by Frank Dobson in September. Key objectives include:

- to provide access for NHS patients to accredited, independent, multimedia background information and advice about their condition
- to provide fast, convenient access for the public to accredited multimedia advice on lifestyle and health, and information to support public involvement in, and understanding of, local and national health service policy development
- to eliminate unnecessary travel and delay for patients by providing remote on-line access to services, specialists and care, wherever practicable.

An Information Strategy for the Modern NHS 1998–2005, Department of Health, 24 September

See it Right

Each year the Royal National Institute for the Blind hosts an awards ceremony, *See it Right*, which highlights examples of good practice in the provision of information to visually impaired people. The Institute is currently inviting nominations for awards. This year's categories do not include "health", but they do include "local authorities" and a "general" category. If you would like to nominate a service, contact the RNIB on its campaign line: 0171 391 2123.

Encouraging involvement

West Essex CHC and the Princess Alexandra Hospital NHS Trust have got together to encourage members of the public to set up and join user groups. They have produced a pack giving background information and ideas on what user groups can achieve. The tone of the pack is positive, stressing that the hospital values contributions from the public.

In exchange for these contributions, the hospital will offer various forms of support, such as a meeting place, administrative support and a representative to act as a link with the group. The hospital has promised that staff members will be available to attend meetings on request and that it will listen and respond to the group's views.

To support the initiative, the CHC is facilitating workshops with hospital staff at all levels, to raise awareness of the importance of public involvement.

Support for family planning clinics

Like NHS trusts elsewhere, Dorset Healthcare Trust decided to close some family planning clinics on the grounds that they duplicated GP services. In view of adverse comment locally, East Dorset CHC and the trust carried out a survey of users' views. The comments below, selected from 781 responses, illustrate the most common reasons why users value the FP service clinics, in many cases preferring them to GP services.

Access and appointments

- "Own GP not doing family planning."
- "My GP ... only offers a daytime service."
- "Trying to make an appointment other than for an emergency is almost impossible at a GP."

Anonymity

- "I prefer the anonymity of the FP service that I cannot get from my GP."

Young people

- "It will cause more young women to take risks as they may not wish to see their own GP."

Expertise

- "FPCs ... are more aware of female needs and are also more up to date with current trials, tests and any problems."

Female doctors

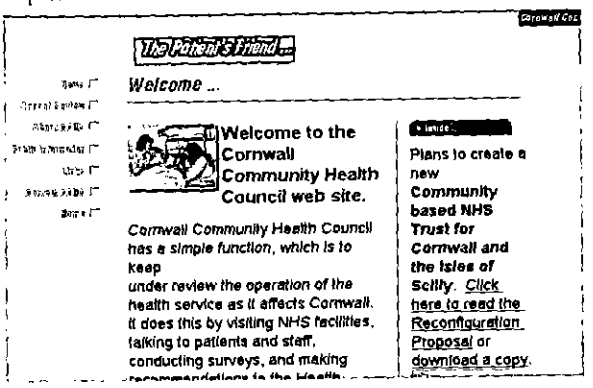
- "You cannot always see a female doctor at your GP surgery."

Report on the changes to family planning services in East Dorset
East Dorset CHC

CHC website

Cornwall CHC is using the Internet to extend the opportunities for informed public involvement in health service decisions.

Cornwall and the Isles of Scilly CHCs have been asked by their regional office to chair a round of public consultation meetings on a proposed merger of two NHS trusts. Cornwall CHC is supplementing the usual ways of informing the public with a website which outlines the reconfiguration proposals. It can be found at: http://www.btinternet.com/~cornwallchc.



Cornwall CHC's website, giving information about the CHC and a local consultation, and links to other sites

What is a health visitor?

Gloucestershire CHC

Unsure about the role of health visitors, members of Gloucestershire CHC decided to familiarise themselves with their work. They met local health visitors and shadowed some at work. They came away impressed with what health visitors do, particularly in relation to health promotion, the wide range of advice they give to mothers and their monitoring of children's development. Health visitors were clearly a valuable link between the mother and other services.

However, there were some concerns, for example:

- It was felt that health visitors need more rights of access to a child when they suspect that something is wrong.
- Some GPs are well aware of the value of the service, but it was felt that other GPs, particularly those who do not work at health centres, may need more understanding of the role.
- The service is overstretched. As it is, health visitors need more clerical support. But the health authority is proposing to reduce expenditure on health visiting by 3%–10%. The CHC believes that a significant reduction would leave many children in need missing out on the service they require.

ACHCEW's new director

Donna Covey took over as director of ACHCEW on 12 October. We wish Toby Harris well in his new activities.

Higher fees for access to records?

ACHCEW has sent a detailed response to a Home Office consultation on legislation to supplement the Data Protection Act 1998 and has also raised concerns about some of the proposals with the health secretary.

Charges for access

There have been problems under the Access to Health Records Act 1990 where some patients have been charged very high sums, in addition to the £10 access charge, to cover the costs of copying and posting records and of providing explanations of older records. The BMA argues that doctors are entitled to charge around £100 an hour for providing such explanations.

Under the new Data Protection Act, patients will no longer have the right to see their records. Instead they will only have the right to information from and about their records. The government intends to keep the maximum charge for access to information from records at £10. However, ACHCEW fears that patients may face additional charges to recover the costs of providing the information even if they do not wish to keep copies and wish only to access the information at the record holder's premises. ACHCEW is concerned that some doctors may try to charge over £100 an hour for work involved in allowing access. This would obviously be a deterrent to many patients.

Recent records

Under the Access to Health Records Act, there was a provision for free access to records which are less than 40 days old. There is no such provision under the Data Protection Act 1998.

Multiple charges

One section of the consultation document raises the possibility of multiple fees to be charged, for example for access to different parts of the "data holding" or for each purpose for which data are processed. Depending on what decisions are made on this, patients wanting access to information about complex past treatments could face many separate charges.

ACHCEW has urged the government to reproduce the previous requirement to give free access to recent medical records and to set a maximum £10 fee, with no additional recovery costs involved.

Members' Code of Conduct

The NHS Executive has set up a working group to review the *Code of Conduct for CHC Members*. ACHCEW sought the views of CHCs on the existing Code and compiled their responses for consideration by the working group. The group has now met – its 11 members include Joyce Struthers, chair of ACHCEW, Mike Smith, Bassetlaw CHC, Pam Eaton, Blackpool CHC, and Ben Griffith, ACHCEW. A draft code is now to be drawn up and considered by Department of Health solicitors. The consultation draft will then be sent to CHCs through their regional offices.

In the Public Interest

As reported in September's *CHC News*, ACHCEW has written to the Institute of Health Service Management, the NHS Confederation and the NHS Executive, the three organisations which sponsored *In the Public Interest*, a report on public participation in the NHS. ACHCEW was concerned about changes that had been made to the final report – making it more negative about CHCs – without reference back to some of the contributors, including ACHCEW.

Judging from responses we have received from the IHSM and the NHS Confederation, the two organisations have a rather different recollection of the process. The IHSM says that comments on the "working draft ... were incorporated" (we do not learn by whom) and:

> "the final draft was then considered by the three sponsoring organisations."

Suzanne Tyler, the Institute's deputy director, insists that she sees a bright future for CHCs and says that she was disappointed at the negative slant on the report which appeared in the *Health Service Journal* – a somewhat naïve response given that the IHSM's press release on the report had led on the comments regarding CHCs since they were the most "radical" and "newsworthy".

By contrast, Stephen Thornton, the chief executive of the NHS Confederation, assures ACHCEW that:

> "the changes to the report which you have identified were nothing to do with the NHS Confederation."

Dissociating himself from an editing process which did not fully involve the relevant parties, he comments that ACHCEW's criticisms are justified.

Suzanne Tyler's letter ends by reiterating the IHSM's commitment to public involvement and referring to seminars it is to hold in November and December on "Really Involving the Public". Details of the seminars appear in *CHC Listings*.