

# PARTNERS



# CHANGE

## QUICK UPDATE ON PROGRESS

- A workshop to launch the programme was held in Glasgow on 2nd May. The report is now available. See extracts on pages 2-3.
- Members of the Partners in Change team have been recruited and most of the secondments from the NHS have now begun. See page 4.
- The Communication of Change project, run by the Dementia Services Development Centre in parallel with Partners in Change, has got underway. See page 5.
- The project team are making contact with people in local areas across Scotland, and we are identifying more examples of involvement and partnerships. See pages 5 and 8.
- The team has begun to explore ways to help participation in areas that are causing some problems for people in many places, and we are now looking for views and suggestions. See details of draft packs and discussion papers, on page 7.

## ACTIVITIES OVER THE NEXT FEW MONTHS

- The first Finding Out Week is in Highland on 23 - 27 July. See page 7.
- Contact with people in local areas
- Work on stroke with Clinical Standards Board and on women's health with the National Health Screening Team. See page 7.
- There will be a second workshop on Outcomes from partnerships between people who use health services and the NHS, probably in September. Let Michelle at the Partners in Change project know if you would like more information.
- We are beginning to commission work from other organisations, including a review of the literature and evidence of methods of involving patients.



# COMMUNITIES AND HEALTH WORKSHOP 2ND MAY 2001

What will the outcomes be from greater partnership between people who use health services and the people who work in services?

A workshop in Glasgow brought together a wide range of people who have experience of using health services and people who work in health and related services across Scotland. The main speakers were Professor John McKnight, who leads the Asset Based Community Development programme at Northwestern University in Chicago, Brian Devlin from Highland Health Board and members of the Braveheart Team, who mentor people with heart conditions in Falkirk.

These are some extracts from the presentations and discussion.

'Over the past few years, people in the health field have begun to use the work 'community' a lot. Why? Well, epidemiologists tell us that there are 5 determinants of health. These influence how often a person is sick and how long the person will live.

1. Our individual behaviour - what we eat, how much we drink, whether we smoke, and so on.
2. Social relationships - whether we have contact with friends, family, and how those relationships are.
3. Our physical environment - what is in the air, where we live.

4. Our economic status: this has well established links with poverty. It also has links with the other factors.
5. The last one is access to medical care.

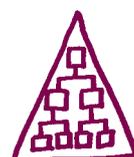
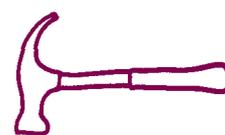
Of these 5 factors, research has shown that access to health care is the least significant. In the United States of America this is usually put at 10% - 13% of the total impact. So the other 4 determinants make up the greatest part of our health and well being. When we think about this, it is very logical to connect communities with health.'

'Both the community and the service system are ways of bringing people together to get something done. But they are very different approaches, and this is why people find it hard when they are working in between communities and organisations or systems - between a circle and a triangle.'

I find it is helpful to think of them as 2 different types of tools, which are useful to do different things - like a saw and a hammer. Each one is different, and neither can do the job of the other. But you can't build a house unless you have both.'



1. CHOICE
2. CARE
3. CITIZENS
4. CAPACITIES



1. CONTROL
  2. LOTS OF SERVICE
  3. CONSUMERS
  4. NEEDS
- (CLIENTS)

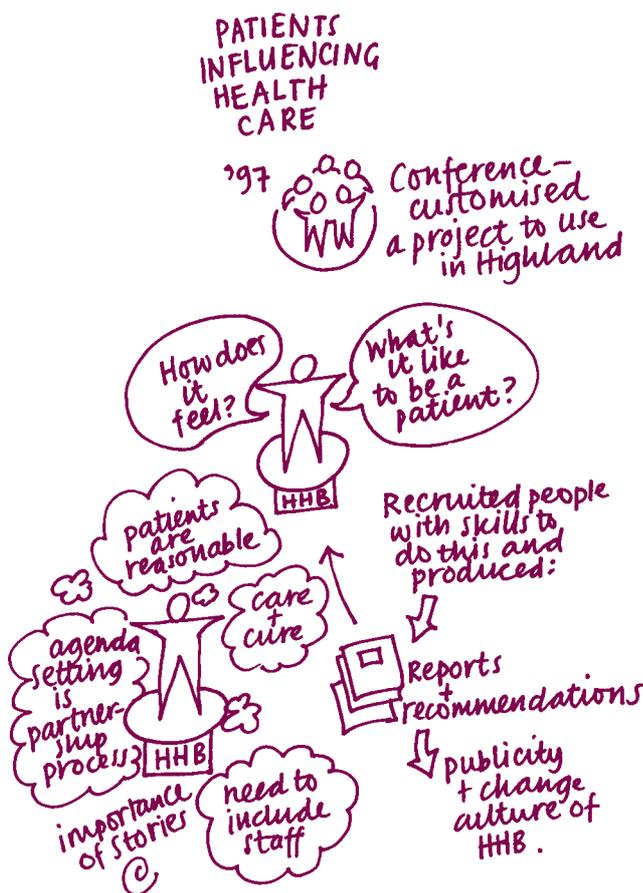
**John McKnight**

'People were generous with their time, and wanted to help make things better for other people as well as for themselves. People did realise that there were going to be financial and practical limits on what was possible. What we did see were patients beginning to make connections across different parts of the NHS in a way that people who work in the service are missing.'

'What has all this shown us at Highland Health Board about partnership with people?

- Partnership needs to be there for a purpose: to make things happen, and to validate and improve our decision making.
- It's messy.
- It involved renegotiating cultures.
- Don't concentrate on the process to the detriment of the outcome.'

**Brian Devlin, Highland Health Board**



'It was good to have an opportunity to put something back, and to use your experience of having had a heart attack to help other people.'

'People had also contributed ideas from their own experience - it isn't just the health professionals knowing it all. For example, local people know more about local resources, and have ideas from other services.'

**Braveheart Team, Falkirk**

What are the outcomes that will follow if we get the partnerships and participation right? Some of the points from the discussion groups were:

- People who are not so assertive and articulate will feel able to engage
- All the people are involved in reforming the service - workers and 'users'
- We think big; we don't just say that things will be difficult and give up
- People are seen as people, not as problems or as illnesses
- Paying attention to the small things, getting them right
- Breaking down barriers - no more jargon, no more language that excludes people or makes you feel small
- Patients and communities have a say in what a good service is
- One measurement is how well health services help people with that illness or condition to live their lives
- Professionals act like people too

The report from the workshop is available from the Partners in Change project and is on the SHS website, [www.shstrust.org.uk](http://www.shstrust.org.uk)

## THE PARTNERS IN CHANGE PROJECT TEAM

HELENA BUCKLEY is seconded from Forth Valley Primary Care NHS Trust where she is Quality Manager. Previous posts have included the State Hospital at Carstairs. Her particular work interests include working with older people from ethnic minority communities and volunteers in health services.

*'In the time I have been with the health service I have found it is the partnerships and staff listening to the people who use our services that make the biggest difference.'*

ANNE CONNOR is Project Manager for Partners in Change. Previous work has included Project Manager for the Allies in Change programme, lead commissioner for mental health services at Lothian Health Board, freelance consultant, researcher in the social work research unit at the Scottish Office, and developing staff-led and user-led evaluations for voluntary organisations.

MICHELLE DAVITT is the Partners in Change project administrator. She has worked in a variety of settings, including as a teacher, in university administration and more recently as a Social Work administrator.

*'I am very excited about joining SHS and becoming part of the Partners in Change project. I feel that all my work experience has been, in one way or another, about helping people and I see Partners in Change as very much a continuation of this satisfying and fulfilling aspect of my working life.'*

PATRICIA MCMAHON is seconded from Borders General Hospital NHS Trust, where she is a Macmillan Nurse specialising in community-based palliative care. Patricia will be working full-time with the project for 6 months from September. Her previous posts have included district nursing and a range of hospital-based settings in Scotland and Ireland.

MAIRI MCMENAMIN is seconded from Ayrshire and Arran Health Board. Until recently she was a Health Promotion Manager, and is now in a new post to lead the Public Involvement, Volunteering and Advocacy agenda for Ayrshire and Arran Health Board. Her background is in Nursing, Social Sciences and Health Promotion. Previous posts have been in Edinburgh and Lanarkshire. Mairi is with the project 2 days a week.

*'I am passionate and energised about involving people. I am very keen to see this project build the capacity for both individuals in the community and for professional staff. I want people to be heard and to shape the services of the future.'*

JUDITH PARKES is seconded from the Inverkeithing Medical Group, where she has been Integrated Care Manager. Judith is full-time with the project.

She has worked in a variety of settings as a social worker and a manager: in local authorities, the voluntary sector, and the health service (in both acute and primary care). This has been in Lothian, Fife and the Borders.

*'In addition to my experience as a professional, my experience of bringing up a large family, having a child with major health problems, being a single parent for a while, and being very ill myself has played a major part in how I see the world and what I feel is important when it comes to services.'*

Other people will be joining the team for particular pieces of work. These include people who come from a user or carer activist background and people from local authorities and voluntary organisations.

### LEAD TEAM MEMBERS FOR HEALTH BOARD AREAS

The Project Team members each take a lead for some Health Board areas. Over the next few months we will be establishing contact with local people in each area.

Argyll and Clyde	Mairi McMenamin
Ayrshire and Arran	Mairi McMenamin
Borders	Judith Parkes
Dumfries and Galloway	Anne Connor
Fife	Anne Connor
Forth Valley	Heather Simmons
Grampian	Patricia McMahon (Anne Connor until Sept.)
Greater Glasgow	Helena Buckley
Highland	Judith Parkes
Lanarkshire	Mairi McMenamin and Helena Buckley
Lothian	Judith Parkes
Orkney	Patricia McMahon (Anne Connor until Sept.)
Shetland	Patricia McMahon (Anne Connor until Sept.)
Tayside	Anne Connor
Western Isles	Helena Buckley

All of the team can be contacted through the project base at SHS on 0131 538 7717.

# FUNDING FOR THE PROJECT

The Partners in Change project received a one-year grant of £450,000 from the Scottish Executive in March 2001.

**Support for local implementation from team, including seconded staff (salaries, travel) £227,000**

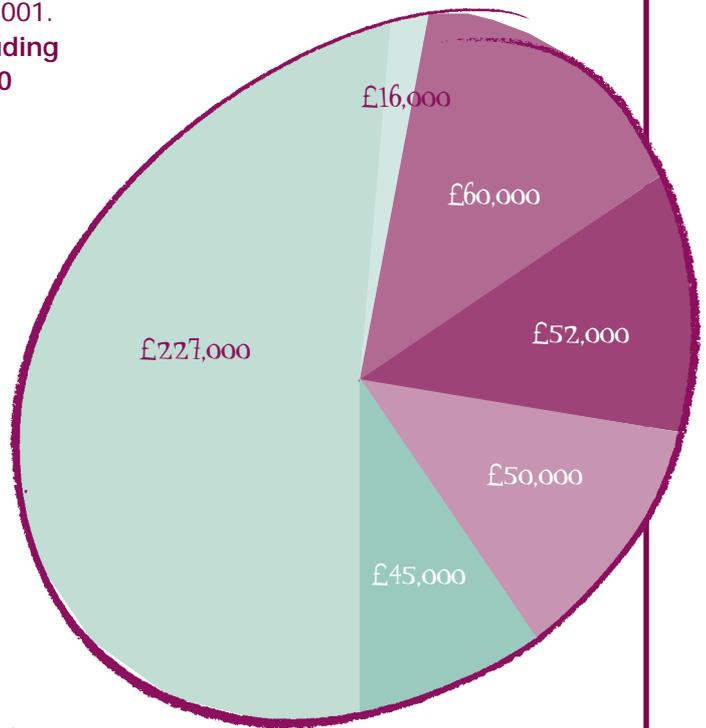
**Sessional workers, work commissioned from other organisations £50,000**

**Local and national events £45,000**

**Publications (multi-media), including newsletters, reports, packs and open learning materials £52,000**

**Project materials £16,000**

**Support from SHS, including accommodation, organising events and management £60,000**



It is hoped that the NHS in Scotland and other organisations will support the project, for example by contributing staff time for specific short projects and helping meet the cost of local events.

## FINDING OUT WEEKS

The Finding Out weeks will enable people in a Health Board area to find out more about the opportunities for participation in their own area:

- what is available in the area
- what issues people think are important
- their ideas for making services and community supports work better
- what would help people and groups to get more involved.

They also feed into the shared learning for people across Scotland.

Most of the local Finding Out Weeks will be in the autumn. There will be regular updates on dates and arrangements on the website, and both the Partners in Change team and local organisers will be circulating information to people and groups in each area.

## Finding Out Week in Highland, 23-27 July

The first Finding Out Week will be in Highland on 23-27 July. The Partners in Change team will be working alongside people from the Board, the NHS Trusts and LHCCs, Health Council, Highland Council, the Community Care Forum and many patient support groups and other voluntary organisations.

Plans include:

- informal discussions in towns and villages across the area with local people, groups and staff
- working with local contacts who can help us arrange discussions in their area, and who will help follow up any matters that arise
- recruiting people to help us with the meetings and discussions - listening to people, facilitating meetings and gathering information and ideas
- bringing together ideas and people from across highland at a Gathering on 10th August in Inverness.

If you would like more information, please contact Michelle Davitt at Partners in Change.

## **PARTNERS IN CHANGE ACTIVITIES THAT ARE GETTING UNDERWAY**

### **How you can help, and how you can get involved**

#### **Checklists for participation in formal meetings**

This is a set of checklists to help make it easier for everyone - but especially people who come from a patient, service user or relative's perspective - to take part in meetings. The checklists were originally developed through the Allies in Change programme, and we have adapted them to suit other situations.

A draft version of the checklists is available on the website or from Michelle at the project office. Please use them if you want to. A few organisations have volunteered to pilot the checklists, and we will be grateful for comments or feedback from other people. A finished set of checklists will be available in the autumn.

#### **Ideas and issues around participation by children and young people**

This paper came from discussions among people with a particular interest in the ways children and young people can get more involved in planning for their own care and for services generally. It is available from the project and on the website.

During the next few months the Partners in Change project and some of the NHS Trusts will be following up the points raised in the paper. In the meantime, you might want to feed in your experience and views. We are keen to hear about examples of ways children or young people are

already contributing their views and ideas, or from people who would be interested in trying out some pilot projects.

#### **Ways to encourage women to use cancer screening and take care of their health**

This is a topic which is emerging as a priority for people in many parts of Scotland. The Partners in Change project is working with the Central Co-ordinating Unit for the National Screening Programme, to look at ways to draw in the experience and ideas of women and of health care staff to encourage women to take care of their own health.

The details will be worked out over the next month or so, but ideas so far include:

- bringing together examples of the good work that is already being done in many local areas
- asking some local projects or women's groups to discuss these issues with a wider range of people, including women who have been reluctant to use these services so far, and to come up with ideas to prompt wider thinking and debate
- bringing together people who work in these areas and people from community projects and women's networks
- bringing together the views and ideas, and feeding these back to people across Scotland, to inform their local planning and organisation of screening and other health services

If you might be interested in helping us look at this area, please get in touch with Judith Parkes through the project office.

#### **What makes a good service and good support for people who have had a stroke?**

The Partners in Change project will be working with the Clinical Standards Board to begin to identify the views and experiences of people who have had a stroke and of their families and friends. This will then feed into the development of standards for health care for stroke patients by the Clinical Standards Board.

At this stage this is a small project, working with local groups and individuals in a few areas. If you would like more information, or if you might be interested in helping us, please contact Helena Buckley through Partners in Change or Sarah Wedgwood at the Clinical Standards Board.

#### **Summary of involvement plans in the HIPs and Community Care Plans**

From early discussions with staff in Health Boards and other settings, it appears that many people find it difficult to get an overview of the work that is already underway or planned to involve or consult with people who might use services.

We have commissioned two researchers to put together a database of the references in the Health Improvement plans and Community Care plans to patient/service user, carer or public involvement. This will be available in September. People in local areas will then be able to update the information as the formal documents are updated and plans are put into action, and link it to information about other patient involvement arrangements.

## COMMUNICATION FOR CHANGE

Communication for Change links closely to the Partners in Change development project that was outlined by the Scottish Executive in section 5 of the Health Plan. The Dementia Services Development Centre (DSDC) is working with SHS who are co-ordinating the development stage of Partners in Change. The Communication for Change project aims to work in partnership with other individuals and organisations, including local NHS settings, local authorities and voluntary organisations. It is funded by the Scottish Executive for one year and will conclude in March 2002.

Communication for Change sets out to explore how people with serious communication difficulties as a result of conditions such as dementia or brain injury can and should be involved in improving services, and to demonstrate practical examples of such involvement. The Centre is committed to working with organisations which focus on other user groups. Any detailed pilot or demonstration project that emerges from this stage is likely to be part of a separate follow on programme.

### DEVELOPMENT OF LOCAL PROJECTS

This will depend on local development concerns and will involve:

- Initial discussions and planning work with the range of key people in the area. We are focusing on local areas, for example LHCCs, as this lends itself more easily to user involvement. Some of the training/capacity building events might cover a wider area. This stage will set the style and values: including people who tend to be excluded, demonstrating partnerships, drawing on the work and ideas that are already there.
- Negotiating and working with existing professional and patient/user networks.
- Widespread distribution of information and lessons, tools and techniques that emerge during the exploratory stage. Participants will also benefit from up to date information on materials on communication and involvement and quality improvement tools currently being developed by the Centre.

### The development team consists of

SYLVIA COX, Planning Consultant, DSDC Project Manager.

SALLY DICK and JANE GRIFFITHS, Consultation and Involvement Trust (CITS).

JOHN KILLICK, Research Fellow, DSDC.

KAREN IRVINE, Graphic Artist and Advocacy Worker.

PAULA RIBEIRA, Research Assistant.

### WORK SO FAR

We have been very busy since March:

- Starting to review the research and development literature.
- Making contacts with people in the field of acquired brain injury and stroke.
- We ran a 'discussion day' in East Fife with people with dementia and their supporters, family carers, local social work, health and voluntary sector professionals, planners
- Exploring potential partners sites.
- We are currently setting up our reference group

**The Communication for Change project still has space for one or two more pilot sites. If you are interested in taking part please contact:**

**Sylvia Cox, Planning Consultant. Email. [s.m.cox@stir.ac.uk](mailto:s.m.cox@stir.ac.uk) Tel. 01786 467740**

## EXAMPLES OF LOCAL THINGS THAT ARE ALREADY HAPPENING

### Information about activities in Scotland: Designed To Involve

Designed To Involve has updated their website, and will be continuing to develop it over the next few months. New parts include:

- many more case examples of what people in the LHCCs and other local settings are doing around Scotland
- references to literature on involvement are now available in a database format
- directory of local contacts, including LHCCs, Community /Care Forums, Health councils, Social Inclusion Partnerships, Health Boards and NHS Trusts and other health-related organisations.

Contact Graeme Waller, Designed to Involve, 24a Palmerston Place, Edinburgh, EH12 5AL. Tel. 0131 220 4101.

[www.designedtoinvolve.org](http://www.designedtoinvolve.org)

### Young people involving other young people: Midlothian Health Care Co-operative

A project to involve young people in Midlothian in identifying ways in which the local health services could be made more accessible, appropriate, approachable, and "user-friendly" for young people was undertaken in Midlothian from January to June 2001, as part of the area's Patient Involvement initiative.

This project worked with a group of 18 young people at Newbattle Community High school, of ages ranging from 12-16 years. The project entailed peer interviewing by a team of young people and group discussions to identify the views, experience and suggestions from young people about the health services they had used, and a group then worked to produce a drama to illustrate and express these issues.

The resultant play was then performed to an audience of local health professionals and policy makers, with a view to raising their awareness of issues the young people wished them to address. A discussion was held following the play between the health professionals and a panel of the young people which particularly focused upon the way certain issues could be taken forward.

Contact: Angela Jackson, Patient Involvement Worker, Midlothian Health Care Co-operative. Tel. 0131 561 5527.

## HOW CAN WE BE PART OF PARTNERS IN CHANGE?

Tell us what you think! Will this be useful for you and your area? Are you doing it all already without the need for any new initiatives? Could you see a better way to organise Partners in Change?

Tell us what you need! What could the project team do to support the development of partnerships in your area between people who use services and people who provide them?

Tell us what you are already doing! We know there is some great work going on out there, but it does not always get reported. Other people would like to hear about your experience so they can make new, more sophisticated mistakes of their own.

Join the team. There are opportunities for people to get involved both locally and nationally.

Start thinking about ideas for local and national projects - and start talking about them to other people.

### For further information about Partners in Change contact

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Michelle Davitt at SHS  
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