The Health Foundation's Co-creating Health Initiative

# Co-creating Health: Engaging Communities with Self Management

## Report and Recommendations

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*Health is created where people live, work, love and play.*
*It is not created in hospitals or made by doctors and nurses. Health is in our hands and in our lives.*

Harry Cayton, DH 2007

# Introduction

This piece of work aims to explore effective methods of engaging communities with self management support and how these may have a future impact on the Co-creating Health (CCH) model. It brings together work from a rapid review of research and current practice (illustrated by five case studies) and also outputs and commentary from two focus groups in CCH sites (Wandsworth Teaching PCT with SW London and St George's Mental Health NHS Trust; Islington and Haringey PCT with Whittington NHS Hospital Trust).

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# Background

With over 17 million people in the UK living with a long term condition and with health services looking at innovative ways to support individuals to manage their own health, we need to look more broadly at how people can be supported to self manage. Generally people access health services for a very small proportion of their time, and either manage their condition effectively by themselves or rely on others for support in the community.

Co-Creating Health (CCH) has developed and is currently testing a number of enablers that support people with long term conditions within the context of the health service. We know that people with long term conditions don't access only health services for everyday support with managing their condition; there are other services available (but not always well advertised or marketed). If self management support is to be truly integrated into all areas of society (and not just the health service), there needs to be joined up thinking between different sectors of society and a drive to embed self management support into everyday life. The time is right to start to widen out the support mechanisms that people can access, map out current availability and identify any gaps.

Integrating self management support into communities in the context of the CCH model needs to be explored further. This report provides examples of how self management support has been integrated into some communities already, and offers recommendations about how the learning from these examples could be applied by CCH.

# Review of the literature about community engagement

## Engaging hard to reach communities

Engagement with self management support can be challenging for many people across communities in the UK. There are some groups of people who are less engaged in wider community activities than others and achieving their engagement with self-management support can be additionally challenging. Glagow et al (2008) includes in these groups: people with low levels of health literacy; of low socio-economic status; or who are from culturally and linguistically diverse communities. All of these groups may struggle to engage with “standard” self management support programs.

Mountain (2006) found that engagement of carers and families is especially important for those who support older people who are frail, with or without cognitive impairment, or those who rely heavily on others for their daily activities.

Fountain et al (2007) acknowledge that community engagement is built on the principles of equality (and social justice) and that barriers to public health/social care services exist for many people. Those barriers are often rooted in the failure of agencies to adequately recognise the complex social, cultural, religious, economic and generational experiences of distinct communities. It further recognises that within some communities there is a lack of awareness about a range of health and social care issues and services. Around some of these issues (for instance, mental health) and within some communities, stigma and denial exist.

Community engagement takes as its starting point the premise that the community itself has the greatest ability to access its own members in order to raise awareness and assess need and agencies have the responsibility to develop services to meet that need. However, the complete body of knowledge required does not lie wholly with either the community or with the agencies. Hence, creating an environment where communities and agencies can share their knowledge will help to fill the gaps.

On a broader level, community development can help people learn about, understand and change the structures and systems that limit their contribution to society (Freire, 1972). It can create social capital which is associated with widening networks, greater trust among local people and more willingness to use local resources including statutory health services (Campbell *et al*, 1999).

L.J. Hanifan's "social capital" is defined as:

> *‘that in life which tends to make these tangible substances count for most in the daily lives of people: namely good will, fellowship, sympathy, and social intercourse among the individuals and families who make up a social unit… The individual is helpless socially, if left to himself… If he*

*comes into contact with his neighbor, and they with other neighbors, there will be accumulation of social capital, which may immediately satisfy his social needs and which may bear a social potentiality sufficient to the*

*substantial improvement of living conditions in the whole community. The community as a whole will benefit by the cooperation of all its parts, while the individual will find in his associations the advantages of the help, the sympathy, and the fellowship of his neighbors (p. 130)'.*

## Engagement as a process - the Community Engagement model

The Community Engagement Model was developed by the Centre for Ethnicity & Health (CEH), now known as the International School for Communities, Rights and Inclusion (ISCRI) at the University of Central Lancashire (Fountain et al, 2007). The model (illustrated in appendix 1) has been developed and tested over a series of projects and has been used mainly in work with black and minority ethnic communities and largely around the issues surrounding drug use, mental health and regeneration.

The model provides a practical framework to ensure services are responsive to the needs of all the communities they serve. It acknowledges that although socially excluded groups are often described as 'hard to reach' or 'hidden', it is not the groups but the providers who fail to find effective mechanisms to engage with them in a meaningful way. This can also be true for communities that are not traditionally viewed as 'hard to reach'.

The Community Engagement Model advocates the following essential components for success:

1. Facilitation by an **independent facilitator**, with the expertise to create the environment in which the engagement can take place. This is a crucial role which has the responsibility to recruit, support and advise individuals who represent their community (and have access to community members)
2. A host **community organisation** with good links to the target community and the infrastructure to support activities (such as a development Trust, New Deal centre, healthy living centre).
3. **Key players** - communities and agencies, who engage together around an issue, e.g. barriers to accessing local services.
4. A focus on a **Task** that is meaningful, time limited and manageable. The process of building the skills and capacities of the community is a significant outcome.
5. **Support** – consisting of Training; Project Support Workers (who are from the communities they serve); Tools & resources - funding, time, expertise, knowledge and a framework for the engagement activity.

Using the model with all of the above key components has proved to be an effective mechanism to aid engagement in the communities in which it has been used. It has not only

been used to successfully understand the barriers communities face in accessing services (health and social care) but has also increased provider understanding of the different segments of the communities they commission and provide for.

The community engagement model is illustrated in Appendix 1 and the identified barriers are illustrated in Appendix 2.

## Successful Engagement Strategies

The following section explores examples of where organisations have been successful in engaging with communities. A case study approach is used to illustrate the approaches that were taken, their achievements and the learning from these.

### Social Action for Health

Social Action for Health (SafH) is a community development charity, which works alongside marginalised local people and their communities towards justice, equality, better health and wellbeing.

Their approach to the complexity of community development is described by the "Spiral of Participation" which is built on the recognition that there are different levels of social organisation and engagement:


They currently operate mainly in East London with 9 full time staff and 120 part time and sessional staff (local people trained by SAfH to work with their community in their mother tongue). There work is at Grass roots level engaging with local people on the issues that concern them.

Amongst a number of objectives SafH encourage local people to take more control of their lives and their health and well-being and, by using local people teach people to manage their own health. By working together with communities they build networks and sustain services for local people by local people.

There are over 20 projects covering a range of topics. The Health Guides Project trains and supports local people to act as own-language health guides within their communities (including Bengali, Somali, Turkish / Kurdish, Congolese, Gugarati, Urdu, Arabic, and English). There are currently 70 active Health Guides within SAfH. They are not volunteers, but paid sessional workers. For many this is the first step towards a career in health related or community development work. This way they not only provide an important interface for the exchange of information, but they also help to raise the economic profile of the local communities.

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### CASE STUDY 1
### A Women's Bangladeshi self management course in Islington

SAfH was commissioned to deliver a self management course (Stanford model) for Islington PCT to female residents of Islington and in Bengali. The PCT identified the need to engage with 'hard to reach' communities to offer the opportunity to access a self management courses.

It was identified that to be able to engage with and get messages across successfully, course tutors leading the sessions needed to be from the same community and are native speakers of the same language (as they are able to have an emphatic understanding of the participants). SAfH has a large number of experienced Bangladeshi self management tutors.

### Action

SAfH did some scoping as to services that were delivered to Bangladeshi and Muslim women in Islington through the Health Guides and Self Management tutors and their families. In this way they found out about the Muslim Welfare House - a mosque located close to Finsbury Park tube and covers the boroughs of Islington, Haringey and Hackney. They were made aware of Arabic/Koran lessons that were taking place for Bangladeshi women twice a week. After making contact with the group coordinator they were invited to one of their sessions to talk about the course.

At the session an outreach worker, who was also a self management tutor, discussed the course and explained the benefits of it. At first people were reluctant to sign up but when they asked questions and got clear answers as to how they would individually benefit the course and also how it could benefit their families, including their mother in laws, they were keen to sign up. At the session about 25 women gave their details.

The women said that they would prefer to have the sessions at the mosque as they knew it and were comfortable in that environment and although they would not mind having the

sessions in a nearby health centre, they would prefer it at the Welfare House. A date was set and nine women attended the first session which then increased to 11 on subsequent dates.

### Achievements and benefits

A comparison of pre-course and post-course showed that:

- Average measures of pain, tiredness, depression and breathlessness all went down
- Average confidence levels in managing pain, tiredness, depression, breathlessness and other symptoms all went up.
- There were no visits to hospital (planned or unplanned) or to A&E in the post- course evaluation. The number of visits to the GP was exactly the same on average.
- A comparison of self management techniques from end course and post course questionnaires:
- There was an increase for all techniques in benefiting the participants conditions between end and post course evaluations
- The technique of most benefit was action planning
- The technique of least benefit was guided imagery which was also reflected in the qualitative feedback.
- The technique that had the most lasting impact was muscle relaxation as it had a higher average score on the post course questionnaire.

### Conclusion

- The right facilitator is needed, who speaks the same native language of the community targeted
- Using community workers to access the community is ideal
- Using existing networks works
- Location is key to engagement
- Identify where the 'hooks' may be (for this group it was how the course could benefit the women's families and mother-in-laws)
- Written follow-up helps with engagement

### Further details

www.safh.org.uk/safh_php/live_site/downloads/islington_report.pdf?gi_session_name=gi_session_4a0c607c334c7

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The work as described in case study 1 is part of SAfH's wider theme of 'Doing Your Part' which is about supporting people in taking control of their own health and well-being and providing them with the skills required to prevent and or manage the impact of ill health on their lives.

There are a range of courses that they offer as support:

- Self management (Lorig 'Stanford' model)
- Good Move! (culturally sensitive body-orientated courses on health and well-being)

- Prevention Programmes (such as the lay-led Diabetes Prevention Programme for the Bengali community in Tower Hamlets which has a strong focus on lay mentors)

The focus for the work is in the London Boroughs of Hackney and Tower Hamlets. All of the courses and programmes are delivered by local people who in their mother tongue, for example, English, Bengali, Somali, Urdu/Hindi, Gujerati and Turkish.

SAfH use a number of different methods to engage with communities and make them aware of support available to them. Another of the methods is illustrated below:

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## CASE STUDY 2
## The Health and Advice Links Project, Tower Hamlets - An innovative way to raise awareness of self management courses

The Health and Advice Links Project in Tower Hamlets is a demonstration of joined up working in practice between the local authority, the primary care trust and local voluntary and community organizations. It was recognized that poverty, poor housing and uncertainty of legal status, lack of educational opportunities all impact on people's health.

The Project started in 2004 and was funded through Neighbourhood Renewal Funding. The project secured the agreement of 8 surgeries supporting advisers in delivering advice to their patients. A partnership between Bromley By Bow Centre, Island Advice Centre, Citizens' Advice Bureau and Limehouse Project was formed. Experienced advisers were then deployed to the surgeries to see patients and give advice on benefits, housing and debt. Patients are referred to the advisers by the practices.

The majority of clients were Bangladeshi (56%) followed by white British (21%), Somali (4%), and black British (3%). Most were between 26 and 60 years (56%), with 37% being older than 60, and 7% under 25 years. Clients were overwhelmingly local to the sessions.

### Action

As well as giving advice the advisers have a role in encouraging patients to take up other activities such as adult learning English classes, self-management courses, volunteering and other community activities. This is a valuable progression for those who have middle term conditions and are receiving health related benefits. This has particular importance given recent changes to Incapacity Benefit which focuses on getting people back to work.

### Achievements and benefits

After four years the service has expanded and the value of the partnership has been immense. There are now sessions running in 17 surgeries across Tower Hamlets along with 5 other practices referring patients into participating neighbouring surgeries. This process has been proven to work well – for instance the Mission Practice take referrals from Blithehale Medical Centre and Globe Town surgery.

Last year the project reached over a thousand new patients and dealt with over four thousand cases. Advisers were able to assist in non-clinical related queries which have lightened the demand on GPs. In many cases, people were assisted with benefit entitlements. Recent evaluation of the project demonstrates how effective the work has been. The study drew on the experiences of a group of patients who experience chronic health conditions which impact on other areas of their lives. HALP advisers have been able to aid these patients in securing significant financial gains through benefit entitlements as well as ongoing emotional gains, principally less stress and worry, greater peace of mind and capacity to relax.

Healthcare professionals who referred patients into the system felt that there had been health benefits for patients who had gained good outcomes (more income, better housing etc.) as a result of using the advice service, including reduction in stress and anxiety, particular benefits to patients where sudden poor health has given rise to the need to sudden life and circumstance changes, and the positive effect on health of gaining disability benefits for patients with these conditions.

Over 80% of those interviewed said that they had health problems and many mentioned multiple health problems. Particularly common problems were back, leg and body pain (13 instances), Diabetes (11), high blood pressure (9), heart disease (8) and Arthritis (8). Nearly 80% would expect to visit their doctor monthly or less.

17 of the 40 people spoken to felt that the advice and service they had received from the Project had made a 'good effect' on their health. The availability of Bengali-speaking advisers was a major advantage for the project but there was a need for more Somali-speakers.

### Conclusion

- Cross referral has worked well with 17 practices across Tower Hamlets along with 5 other practices referring patients into participating neighbouring surgeries.
- Advisers were able to assist in non-clinical related queries which have lightened the demand on GPs.
- Patients who experience chronic health conditions reported impacts on other areas of their lives - securing significant financial gains through benefit entitlements, ongoing emotional gains, less stress and worry, greater peace of mind and capacity to relax.
- Healthcare professionals who referred patients into the system felt that there had been health benefits for patients who had gained good outcomes (more income, better housing) as a result of using the advice service.

### Further details:

The full report can be accessed at:
www.safh.org.uk/safh_php/live_site/downloads/health_and_advice_links_project.pdf?gi_session_name=gi_session_4a0bf50dc06da

SAfH have found that when there is flexibility within the system to allow groups to take 'ownership' the results are incredible:

> ***"Our last self management course was run with a small group of Bengali women in North West part of Hackney. This group usually met every fortnight but agreed to change their meeting pattern in order to do the course. The result was very good. The drop out rate was zero with all eight women completing the course. We were very pleased with this record and the women were pleased with the course."***
>
> **(SAfH, 2006a)**

## An International Approach – Learning from Australia

The Australian population has encompassed an increasingly diverse mix of cultures, languages, and beliefs over recent years (like the UK population). With this comes a challenge concerning influencing lifestyle behaviours, literacy, health and wellness expectations, and ownership of lifestyle choices for a number of culturally-diverse communities and people.

In Australia, approximately 70% of the national burden of disease is attributed to chronic conditions and predicted to rise to near 80% by 2020 if present trends in health care continue. Life expectancy for indigenous Australians (SA) is unacceptably low. Through improving chronic condition management, it is hoped to reverse or at least slow the impact of chronic disease on mortality and morbidity rates amongst local Aboriginal Australians (National Public Health Partnership, 2001).

There are number of formal and informal self management models being used around Australia. However, the dominant model is the Lorig "Stanford model" - Chronic Disease Self Management Program. A pilot study was done to explore reports from primary health workers in one large regional community health service that the Stanford model was generally unsuitable, and ineffective for, many of their clients. Health workers deduced this from lack of client interest in attending courses, high rates of failure to attend the first booked session, high subsequent drop-out rates, and consistent negative client feedback.

Many people in the health region were from vulnerable and disadvantaged groups, including clients with long term mental health conditions, low intellectual ability, Indigenous Australians, new migrants and refugees from a range of ethnic groups, and unemployed, homeless and/or illiterate people.

## CASE STUDY 3
## Supporting Aboriginal communities with Diabetes

The Chronic Disease Self Management (CDSM) strategy for Aboriginal people on Eyre Peninsula, South Australia, was designed to develop and trial program tools and processes for goal setting, behaviour change and self-management for Aboriginal people with diabetes. The project was established as a pilot programme to test and trial a range of CDSM processes and procedures within Aboriginal communities. Over a one-year period, 60 Aboriginal people with type-2 diabetes in two remote regional centres participated in the pilot program. This represents around 25% of the known Aboriginal diabetic population in these sites.

### Action

A community development approach was used to engage with participants. Four community Aboriginal Health Workers (AHWs) were trained in goal setting and self-management strategies to enable them to run the program.

The AHWs worked with people in small groups within their own communities to help enable them identify and understand their health problems, develop specific condition management goals and person-centred solutions. The process was enabled by community concern regarding the prevalence and mortality associated with Diabetes.

The barriers identified by the participants were reported as their families and social dysfunction, access to services, nutrition and exercise. The Aboriginal Health Workers identified that barriers include lack of preventative health services, social problems and time pressure on staff.

### Achievements and benefits

Whilst the QOL score showed no significant change, self management scores improved in five of six domains. Problem solving improved by 12% and goals by 26%, mean HbA1c reduced from 8.74-8.09.

It was concluded that a diabetes self management program provided by Aboriginal Health Workers is acceptable, improves self management and is seen to be useful by Aboriginal communities. Results suggest that when modifications are made to ensure programmes are culturally inclusive of Aboriginal people they can be effective strategies for improving self-management skills and health related behaviours of patients with chronic illness.

The CDSM pilot study in Aboriginal communities has led to further refinement of the tools and processes used in chronic illness self-management programmes for Aboriginal people and to greater acceptance of these processes in the communities involved. Enablers include community concern regarding the prevalence and mortality associated with diabetes.

## Conclusions

Participation in a diabetes self-management program run by Aboriginal Community Health Workers enable people to identify and understand their health problems and develop condition management goals and person-centred solutions that can lead to improved health and wellbeing. While the development of self-management tools and strategies led to improvements in participation and health outcomes, the pilot program and the refinement of new assessment tools used to assist this process has been the significant outcome of the project. The CDSM process described here is a valuable strategy for educating and supporting people with chronic conditions and in gaining their participation in programmes designed to improve the way they manage their illness.

## Further details

Battersby, M.W., Kit,J. A., Prideaux, C. Harvey,P. W., Collins, J. P. Mills, P.D. (2008) Research Implementing the Flinders Model of Self-management Support with Aboriginal People who have Diabetes: Findings from a Pilot Study, Australian Journal of Primary Health 14(1) 66 – 74, 2008

Kit ,J, A. H., Prideaux, C., Harvey,P.W., Collins, J., Battersby, ,M., Mills, P. D. Dansie, S (2003) Chronic disease self-management in Aboriginal Communities: Towards a sustainable program of care in rural communities, Australian Journal of Primary Health 9(3) 168 – 176, 2003

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There is an internationally-recognised need to tailor self management messages for people from ethnic and socially disadvantaged backgrounds to optimise uptake of ‘ownership’ of their condition.

The pilot identified consistent messages and themes resulting in the production of nine guiding principles, as outlined in the table on the next page:

1. Engage clients in the most appropriate forum for them, by developing effective networks to increase community awareness and access to relevant courses and information.

2. Use existing broader activity and program structures to engage specific groups of people.

3. Engage appropriately skilled facilitators who understand the cultural sensitivities and are able to communicate effectively with the groups.

4. Adapt course content and structure to meet the needs of each group.

5. Structure self management education strategies to celebrate and encourage shared stories and experiences, which may not have an overt focus on illness or health.

6. Focus on health rather than illness – health as part of an individual, reflecting peoples culture, family, living environment, community and capacity to make healthy behaviour choices.

7. Maintain regular contact with clients at the pre-contemplation stages to enable them to access appropriate supports, health workers and services when the time is right for them.

8. Accept that not all group participants wish to change health behaviours; therefore, focus on what individuals can and want to do and what they are able to change.

9. Ensure program evaluation acknowledges and captures changes at all levels of behaviour change, including pre-contemplation and contemplation levels.

The “Living Improvements For Everyone” course, known as the “LIFE” course is testament to the need to tailor courses to the need of the community targeted. The program is based on the Stanford model, with modifications making it more culturally appropriate for Aboriginal and Torres Strait Islander populations. Modifications arose and included:

- changing the name of the course (“LIFE” considered to be more marketable and user-friendly)
- Introducing a “grief cycle”, as it was identified that many participants were preoccupied with grief, making it hard for them to deal with their long term condition.
- Extensive scripting of the course notes to make it easier for leaders to use.
- changing the language to improve cultural appropriateness (and eliminate jargon), and
- Increased peer leader support.

*Identified barriers*
Cultural norms and the way things were "back home" significantly impacted on their current health behaviours. It was identified that recognition needed to be paid to peoples' past experiences and their broader community, social, economic and environmental health concerns. These factors had a big impact on their motivation to take control and whether they were prepared to take a proactive approach to the management of their LTC.

*Beliefs*
Many migrant parents believed that a "big child" (overweight) was an example that the parents were "doing well" and were able to provide adequately for the family (underweight=poverty) Numerous examples of parents providing children with unhealthy food and supporting unhealthy food choices, because such food choices were freely advertised. They believed that media advertising was "Australian" and they wanted their children to be seen to be as "Australian" and not be different. Many migrant clients came from countries where media and advertising has been strictly controlled by Government. They thus believed that if foods were advertised in Australia, they must be Government-supported or approved, and thus "good for you" (advertised=approved, healthy). Previous experience of poverty, or having lived in situations where food was controlled and scarce (such as refugee camps) put a different perspective on food availability and eating for many migrant families.

*Culture*
The issues around the broader understanding of long term conditions (and the influences of culture and past experiences) on managing health were highlighted by Warren et al. in their research and development of the LIFE course. These issues were practically addressed in the LIFE course by creating a name for the course that had meaning, and modifying the model to incorporate cultural issues that influenced clients' ability to manage their long term condition.

Different cultures required different approaches and these required experienced peer leadership to understand what worked and what didn't.

**Identified effective strategies**

*Using established groups*
Using established groups or structures, and using non-health-related opportunities appeared to work far better in retaining people's interest and commitment than a illness-focused groups. Expectant mother's (parents) groups, mothers and babies groups, sewing and cooking groups, shopping groups, young adults' social groups and men's sports groups were cited as opportunities to bring people together to share stories which could be given a "wellness", "risk minimization" or "good health focus" by an experienced facilitator. Peers who had made significant health changes were often successful as "role models" and "peer leaders" particularly if they were able to identify with the barriers faced by others in the group when making similar changes.

*Courses held in community settings*
It was suggested that the place of delivery was often key to assisting clients to change health behaviours, as some may be reluctant to attend a health care setting, yet may be open to being visited at home or attending a neutral non-health community location. This flexible approach to long term condition self-management has been recognised in the literature as one of the essential factors to advancing self-management in Australia.

*Shared group experiences*
An important message from the work done was the value of shared group experiences, bringing people together to share stories and learn from each other. It was identified that groups should be fun, and people should want to attend each meeting rather that being expected to attend.

*Embracing diversity*
Successful groups focused on: experiences and good health; knowledge built on established strengths and skill; different methods of communication (written, conversation, dance, visuals); celebrating and embracing social, emotional and cultural intelligence.

*Community facilitator*
The facilitator had a pivotal role to play in ensuring that groups came together, stayed together, had fun and learned something. They needed to be credible and experienced and have the ability to:

- understand and manage group dynamics
- be culturally sensitive (same culture as group members or with demonstrable awareness of cultural needs)
- understand languages (other than English) and enable the involvement of language-challenged individuals
- communicate using idioms/phrases recognisable by all participants
- be non-judgemental and fun (yet respectful of the individual's and the group's boundaries and limitations)
- not impose their own views
- value all individuals in the group and allow them to be heard
- establish and maintain group cohesion
- celebrate teachings and learning's within the group
- empathise with group experiences
- actively support, and be involved in, clients' change processes
- appropriately challenge and engage in debate about different beliefs and interpretations of health/social messages
- disseminate health messages

The importance of good group leadership was acknowledged by the LIFE course with increased support of the facilitator and a concerted effort to recruit course participants as leaders once they had finished the programme.

Good facilitators should involve clients in determining what groups will achieve in the short and long term and how the group sessions are structured and run. Session content, goals, outcomes and organisation need to be a group decision, facilitated by the leader. The facilitator needs to have the skills to change group structures/roles/goals as required and to support the group to follow its own path within a self-management framework.

Nine draft guiding principles (see above) were distilled from the pilot and may be useful for others who are working with vulnerable and disadvantaged clients with a disappointing level of engagement in formal self management courses.

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## Learning from the North West of England

As has been illustrated by the work in Australia, the setting – in the community – and leadership by community workers are both key to success. Oldham wanted to engage with people to change health behaviours and were aware that the target audiences may be reluctant to attend a health care setting, and so neutral non-health community locations were essential.

Oldham has areas of high health inequalities and the gap is not closing. The 'Self Care for You' course was seen as one of a number of initiatives that could begin to address the gap.

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### CASE STUDY 4
### "Self Care for Everyone"

'Self Care for You', a self care skills training course, was developed by the Working in Partnership Programme (WiPP), and Oldham PCT was one of three PCTs who piloted the course. Provision of the course in Oldham is now run through NHS Oldham and Oldham Community Health Services (OCHS) and was set up with the main aim to help people to take more control over their own health through information and knowledge, so to achieve a better quality of life for themselves, their families and friends.

#### Action

Extensive work has been done through the local community, by engaging in outreach and promotion. A variety of people from different settings have been provided with information about Self Care training opportunities.

Once people have been identified, they are allocated a space on a course that is local to them and will be given the specific information about the times and venue. One of the objectives is to be as flexible as possible in the approach to setting up courses, and making provisions for people where needed. This can often include the allocation of lunch, crèche facilities and sometimes a translator, but also the ability to approach each session with an open mind and have the option to alter or adapt where needed. The training in total lasts 9

hours. It is delivered in a variety of different time frames (dependent on the group preferences and is free of charge.

A broad range of subjects are covered to help individuals make more informed choices regarding their health and well being, empowering individuals to take ownership of their own health choices in life, through better knowledge and a greater understanding of what's available for them to access within their local community.

The team: a Self Care Coordinator; Self Care Development Worker; and a group of volunteers offer a package of Self Care support. They are currently developing culturally appropriate packages tailored to the specific needs of targeted community groups. In addition, the NHS Health Trainer Service is promoted at the end of every course. This allows participants to access ongoing, one-to-one support after the course has finished and helps them to implement some of the lifestyle changes they may have identified. One of the core messages is "Self Care is for everyone", with the vision to deliver training to as many people as possible (and so tackle as many barriers as possible to people accessing the service).

Provision of crèche facilities is offered and lunch as a further incentive. To date over 45 courses have been run approx (86% women, 14% men). Of the courses run, 35% of individuals were from BME communities. The team is continuing to develop pathways within several key Primary Care settings within Oldham and has been actively promoted and offered out to patients / clients at a variety of primary care locations in Oldham. These include the Walk In Centre. As of September 2008, there were 47 trainers registered to deliver the course.

Monitoring and Evaluation - Data is collected to better understand not only the needs of the individual, but also what changes they may wish to make/ have made within their lives (including lifestyle information around smoking, alcohol intake, medical conditions and data around physical activities and consumption of fruit and vegetables). In addition to this, an evaluation sheet tracks the individual through the training to capture changes to self care, self esteem and anxiety levels.

The Self Care Team listen to what people have to say about the courses and take on board any advice or recommendations from people. This is in part, is why the project continues to be successful in its approach to integrated community health.

### Achievements and benefits

Leeds Metropolitan University undertook a large-scale quasi-experimental study with a longitudinal element tracking individuals who have been through the intervention at baseline, 6 months and 12 months. The findings are to be published later this year but early indications show that in the intervention group (over 750 people) as a whole there was a significant increase in Self Esteem relative to the control group.

Participants reported increased awareness of their health and their self management of their health and an increased confidence and motivation to initiate and maintain change in their lifestyle. There were examples of participants who had health conditions that had reported improvements, for instance reduction in hypertension as a result of weight loss and increased exercise.

'Self Care for You' is seen by stakeholders as having a powerful core message within a flexible framework. It is relevant as it enhances existing activity and meets wider organisational goals in many of the organisations where it is delivered. It is seen as a good way of improving personal health, raising self esteem and gaining life skills in relation to health and wellbeing and an effective way to engage members of the community who may be viewed as 'hard to reach'.

Via a flexible approach people are inspired and will often use the course as a spring board to further development. At follow up sessions the majority of participants report continued development and an altered outlook through the small changes they have made (and the effects the changes are continuing to have on their lives).

With the training being provided without cost to the service user, and the ability to run the training in a variety of community settings, the team are able to engage with a vast range of people from the culturally diverse town.

### Partnerships

This work has had a community-based approach which has been supported by multi-agency involvement for its promotion and development (linking with a variety of community projects as well as local employers, schools, youth centres, faith groups and NHS trusts).

Ongoing work with different organisations has not only informed the project but also provided regular service users who are keen to access courses. A recent example of this is the successful linkages with local Children's Centre's where the team were able to promote the courses we run to parents and also deliver the training at the very centre the parents' access on a daily basis. The team have had the opportunity to develop a real partnership with staff at all of these venues, enabling them to promote and refer service users to the project so we are often able to provide training at these venues on a rolling programme.

### Conclusions

- The 'Self Care for You' course allows for an open dialogue to exist between client and provider, and is also a success due to the clear communication of key messages, and information about services available.
- The course aims to provide people with a far greater understanding of the healthcare system, what they can access, and when it is appropriate to access it.
- Through the course an individual is given the opportunity to access a wide range of services to support them with their health behaviours. Gaining greater knowledge, making links with the new Health Trainer Scheme; accessing a range of social

networks linked to the Health Improvement Service. There is a pathway into further development and maintenance of lifestyle changes.

- The course looks at anxiety and stresses within day-to-day life, the short and long-term effects, and how it can link to potential long-term conditions. It offers a variety of alternative methods and solutions to productively deal with stresses and anxiety and further emphasises the holistic concept.
- Work is based within local communities. A solid multi-agency approach is at the forefront of the work carried out, and generally people accessing the courses have better knowledge of choices and make for a better informed person.

### Issues / lessons learnt

- Most importantly self care needs to be embedded in the community to make it as accessible as possible. Where necessary and appropriate the course has been delivered by bilingual trainers, thus making the course accessible to Oldham's black minority ethnic (BME) communities. Many of Oldham's self care trainers are from the communities in which the vast majority of the courses are held. The trainers are able to relate directly to participants experiences. Such empathy has been the key to the success of the project.
- It is essential that courses are delivered by competent trainers. The current Health Improvement Manager who established the project is a self care associate trainer, i.e. a trainer of trainers. This is an important role in developing and ultimately expanding the project. Once trained self care trainers train with experienced staff until they are competent and confident to train on their own. A buddy/mentoring system has proven to be successful in supporting new trainers. A trainer's manual has been produced to assist in the delivery of the course. Participant manuals are distributed at the beginning of each course, providing a step-by-step guide to enable participants to follow the course and to read between sessions if they so wish. Personal assessment/reflection forms are included in the manuals, as are course evaluation forms. Such materials have been adapted for different settings, GP practices, workplaces etc and different target groups such as young people.
- Whilst provision of translation is made, it is not always cost effective. The team have found that through the involvement of people in delivery, with support and development opportunities individuals from a variety of backgrounds and community groups help make sure the key messages get across.

### Further details

For any further information regarding the Self Care Project within Oldham, please feel free to contact:

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## Bromley by Bow

As highlighted by the work done in Oldham a holistic model of support is needed if engagement is going to be at an optimum. This is something which is also illustrated by the Bromley by Bow work.

There are high levels of chronic physical illnesses and mental health problems in the community in the Bromley by Bow Centre serves. It is widely accepted that these are often due to the social circumstances within which people are living. Therefore, the Bromley by Bow Centre's approach to health and well-being is holistic and is continually seeking to innovate and support people towards a healthier lifestyle.

At the core is the GP practice and the healthy living centre which offers the wide array of services that you would expect from a modern forward-looking primary care facility. There is a health trainers' programme which supports people to manage their own health. It is recognised that local people are often the best route to promoting wellbeing in the community. Better nutrition and more exercise is seen as the easiest way to make a major impact on the health of the community.

Their 'Working Wonders' enterprise offers a full daycare service for vulnerable adults as well as opportunities to take part in creative arts activites and to create a community flower garden. A Children's Centre offers a whole range of projects for parents, families and children under 5.

The Centre promotes a holistic approach to wellbeing through its support of 'Inside Out': a social enterprise which delivers a broad range of complementary therapies in conjunction with the Bromley by Bow Centre.

They pioneered the 'exercise on prescription' idea in 1997 and this led on to the development of the healthy living programme with over 300 regular participants. An outline of the programme is detailed below:

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**CASE STUDY 5**
**Healthy Living Programme**

The Healthy Living Programme has a multidimensional framework, which is modified and adapted to a person's needs, age, gender, and general health status. Individuals can choose the method of support, which depends on the advancement and complexity of their general health status.

The programme incorporates two dimensions of preventative care: Primary and Secondary. *Primary prevention* aims at reducing the risk factors that lead to development of ill health, such as heart disease, hypertension, diabetes, circulation problems and osteoporosis. The risk factors include poor eating habits, being overweight/ obesity, lack of exercise or prolonged immobility, smoking, alcohol misuse, excessive stress and depression. With support and guidance on making some lifestyle modifications, the risks can be greatly

reduced. *Secondary prevention* enables people with long-term illnesses, chronic pain and disabilities to cope better with their limitations, anxiety and depression that result from the long term condition. Healthier lifestyles, weight control and Personal Management Plans can greatly reduce their risk factors that lead to more severe health problems.

The programme enables people both to cope better with their limitations and to enhance their optimum body functioning, which help them to resume more active ways of living. This, in turn, can help them to improve and increase control of their functional abilities and to minimise the risk factors that often predispose development of more severe health complications.

The work is based on building people's capacity to improve and increase control of their general health, which integrates the physical, cognitive and social aspects of their health.

### Action

The centre runs open days and awareness raising workshops for the community in which it serves. People are invited along to see what the centre has to offer them. The Healthy Living Programme is offered alongside this. However, the majority of people who are engaged are referred into the programme by a healthcare professional (but people have the option to self-refer). Individuals are invited to a one-to-one consultation which explores the needs of the individuals. Specific outcomes are agreed as a part of the consultation and a specific individualised personal management plan is devised. Dependent on the outcomes identified, the individual is given a number of options to consider and will be invited to participate in practical sessions such as:

- Food for health & weight control
- Balancing active lifestyles with medical care
- Coping methods: coping better with chronic pain, long-term illness or disability; coping with stress and anxiety/ support for carers

A physical management programme may contain:

- Muscoskeletal Exercise
- Cardiovascular & Respiratory Exercise

Dependent on the needs identified, the individual may be supported through an agreed number of weeks programme i.e. 6 week, 12 weeks. However, once this is completed people are always welcome to participate in sessions on an ongoing basis if desired. Some people have been engaged with the programme for a number of years.

### Achievements and benefits

The programme has been evaluated qualitatively and quantitatively and has been found to be of huge benefit both in physical and mental health.

574 mixed ability men and women have participated in both activities from April 2007 to March 2009, and their ages ranged from 14 to 98 years old. 50%, who presented chronic conditions and disabilities, attended the activities as part of their continuing participation and long-term management of active lifestyles. The outcomes from the work are detailed below:

### Physical benefits

- Blood pressure and resting heart rate have decreased and remained stable
- Blood circulation has improved
- Manageable respiratory system efficiency – not so short of breath whilst performing daily living tasks, which reduced the recurrence of panic attacks
- Increased strength in legs improved stability of walking/ standing – less tripping and falling – reduced risk of accidents and injuries
- Stronger musculature, increased stamina & endurance, easier weight-bearing, more self-sufficient and less dependent /enhanced independent living
- Joints became more flexible/ reduced stiffness – better coping with daily activities and more efficient personal care
- Enhanced weight-bearing activities, dietary modifications and outdoor walking strengthened the bone density, which was demonstrated in DEXA scan - crucial in management of osteoporosis

### Cognitive & Social benefits

- Increased self-esteem and confidence to make healthier choices in daily living enabled to maintain the gains within long-term health management issues.
- More optimistic and positive attitude to life has reduced depression
- Improved self-perception and interpersonal communication skills have encouraged the motivation to build on the existing abilities that enhanced individuals' quality of living.

### Conclusions

- Having a flexible framework, which can be modified to a person's needs, age, gender, and general health status is effective.
- The programme has helped to reduce risk factors and promoted better general health both physically and mentally.
- Enabling individuals to choose a method of support, dependent on their general health status brings benefits.
- The programme has encouraged individuals and motivated them to build on the existing abilities that enhance individuals' quality of living.

### Further details

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# Review of community engagement in self management support at two CCH sites

Two CCH sites contributed to a review of activities taking place locally to engage communities in self management support for Long Term Conditions and some wider public health issues e.g. obesity:

- Wandsworth Teaching PCT, SW London and St George's Mental Health NHS Trust
- Islington and Haringey PCTs and Whittington NHS Hospital Trust

A focus group was held at each site. A non-directive facilitated approach was taken at the focus groups allowing the attendees to openly express their experiences, views and opinions. They were asked to identify local examples of successful community engagement in self management support, articulate why they were successful and also identify examples where it was unsuccessful and why. The groups then identified possible future strategies to support the successful engagement of their local communities in self management support and the potential obstacles that may stand in the way. The full reports from both focus groups can be found in Appendices 3 and 4.

The outputs of the focus groups reported in Appendices 3 and 4 support the theory identified in this report in terms of when and where community engagement has worked well. For example, the community engagement model identified in Section 3.2 of this report advocates using expert independent facilitators; working with community organisations with strong links to the target community; having a manageable task that is supported by appropriate resources. The learning about successful community engagement from the two CCH sites involved in this review supports this.

Some of the work carried out at the 2 CCH sites to improve community engagement also indicates that engaging people through using creative activities e.g. sport and cooking provides the motivation to participate. Creative activities need to take place in and using an appropriate forum and aim to meet the needs of the individuals attending by focusing on what they are willing and able to change in their lives.

Partnership working, creative activities, venues based in the community, using listening approaches, localised focus, open mindedness to wants and needs, being responsive to requirement and role modelling are all key requirements identified at the focus group to engaging and working successfully with communities. Examples identified where engagement wasn't successful included being prescriptive about the perceived values / wants / needs of the community; lack of cultural sensitivity; poor marketing and communication of community based activities; not being fully engaged with the voluntary sector.

To support community engagement in the future the group identified that building better co-ordinated relationships with community leaders and the Voluntary Community Faith Sector

(VCFS) by providing the right infrastructure was vital. Engagement needs to be bottom-up through building trust; one way of helping to achieve this is to meet in accessible non-threatening locations / environments. A delivery model suggested by one of the focus groups uses existing Health Trainers who have already built relationships in their local communities and who could also support other health workers to improve their community development skills. The focus groups also identified that making GPs accountable for self management would facilitate embedding the partnership approach that is required. They also identified that there is a need for a cultural change within health services to support the self management approach.

Future obstacles to successfully engaging communities in self management support that were identified included the hierarchy within the health service and the continuation of the traditional paternalistic approach to health care. Health care professionals tend to prefer traditional approaches to managing long term conditions and the apparent lack of evidence to support the implementation of self management can be a barrier to changing this.

# Conclusion

This report acknowledges that most people need to be able to access support to help them manage their long term conditions outside of traditional health and social care services. The report identifies a number of key factors that could aid the successful engagement of local communities in developing and using community based self management support

A community development approach could help build greater trust among local people and more willingness to develop and use local resources. However, it is important that the development process is supported with a structure and a number of key components (as outlined in the community engagement model developed by the University of Central Lancashire).

It is important to create an environment where local communities and provider agencies can share knowledge to fill gaps in information. This is crucial for groups who are less engaged than others and who may struggle with "standard" self management support programmes.

A key point from a number of the case studies is that self management support has to be about personal choice and it is important that people are engaged in the most appropriate forum for them. Therefore, for some people simply being referred is not enough to engage them. The social model of health acknowledges patients as people first and foremost and focuses on health rather than illness – reflecting a person's culture, family, living environment, community and capacity to make healthy behaviour choices. As suggested, the community itself has the greatest ability to access its own members.

In CCH, there are some SMP programmes that take place in community halls, but the overwhelming majority take place in health care buildings. These facilities are not usually places where people would naturally gravitate towards for social activities. A number of the case studies found that making people feel comfortable and at ease is crucial and so the location of where support is offered needs to be given careful consideration: a neutral non-health community location is ideal. By using community settings it reinforces the social model of health by giving a message to people that self management support is much wider than the healthcare professional team and services.

All of the case studies identify that the right facilitator for self management activities is important and he/she should ideally speak the same native language of the community targeted. By using community workers to access the community, the engagement is likely to be viewed as trusted and purposeful. Different cultures need different approaches and these require experienced peer leadership to clearly understand the effective strategies and mechanisms that work in engaging people. Community workers are able to tap into opportunities available such as existing networks of people, help to identify where the 'hooks' to engagement may be and are able to engage in an ongoing plan for follow ups to support people in their goal achievements. When there is flexibility within the system to allow

groups to take ownership, the drop-out rates from self management activities are low and results are good.

It is important to consider if there are any 'hooks' for particular communities or groups. For the group in Islington the hook was how the course could benefit the women's families and mother-in-laws. For the group in Tower Hamlets who had access to the Health and Advice Link Advisers, securing significant financial gains through benefit entitlements also gave them emotional gains i.e. less stress and worry which increased their capacity to relax and participate.

It needs to be accepted that not everyone will want to make changes to health behaviours. There should therefore be a focus on what individuals can and want to do and on what they are able to change. It should be ensured that contact is maintained with people who are not even considering making any changes, to enable them to access appropriate support health workers and services when the time is right for them.

There are a number of effective components that are common to the approaches that have been outlined in this report. These are summarised in Table 1 below:

| **Components** | Case study 1 Women's Bangladeshi SM Course Islington | Case study 2 Health & Advice Links Project | Case study 3 Supporting Aboriginal Communities | Case study 4 Self Care for You North West | Case study 5 Healthy Living Programme |
|---|---|---|---|---|---|
| Community tutors | | | | | |
| Community host organisation | | | | | |
| Flexibility to adapt approach | | | | | |
| Setting within non-health related venue | | | | | |
| Focus on holistic health not illness | | | | | |
| Identifying hooks | | | | | |
| Adapting communication methods | | | | | |
| **Key** | **Yes** | **Unknown** | **No** | | |

Table 1

# Recommendations

The findings in this report offer many openings for the current and future delivery of the CCH model. Until now, most of the self management programmes have been delivered in health settings and there may be gains if this were widened out to different community settings.

In order to achieve this there is a need to review the current approach to SMP in light of this report and develop a plan of activity to support the engagement of communities in self management support. This review and plan should take account of:

- Community groups in each of the eight existing CCH sites as there may be opportunities to learn from them during the last year of the this phase of the programme
- Opportunities to experiment with new approaches to improving community engagement in self management support during the last year of this phase of CCH
- The infrastructure and current work within the 39 'regeneration sites' identified by New Deal for Communities as this could offer a potential platform for the CCH model for Phase 2.
- Current programmes and work-streams that have a focus on the wider determinants of health such as the Adults facing Chronic Exclusion Programme (ACE) and consider collaborative working to potentially create a joined up approach to supporting self management (further work needs to be done to identify these).

# References


Battersby, M.W., Kit,J. A., Prideaux, C. Harvey,P. W., Collins, J. P. Mills, P.D. (2008) Research Implementing the Flinders Model of Self-management Support with Aboriginal People who have Diabetes: Findings from a Pilot Study, Australian Journal of Primary Health 14(1) 66 – 74, 2008

Bohata, K., Reynolds, S., Drennan, R., & Overton, C. (2002) *Engaging Communities in Learning: A Report of research undertaken by Dysg on behalf of the National Council ELWa*

Boldy, D., & Silfo, E. (2006) 'Chronic disease self-management by people from lower socioeconomic backgrounds', *Journal of Integrated Care*, 14:4, 19-25

Borkman, T., Karlsson, M., Munn-Giddings, C., & Smith, L. (2005) *Self-Help and Mental Health: Case Studies of Mental Health and Self Help Organisations in US, England and Sweden.* Stockholm: Skondalsinstitutets Research Department

Campbell, C., Wood, R., & Kelly, M. (1999) *Social Capital and Health.* London: Health Education Authority

Coulthard, Warren K., F. Harvey, P. (2005) 'Elements of successful chronic condition self-management program for indigenous Australians', via http:/www.abc.net.au/rural/events/ruralhealth/2005/papers/selfmanagement.pdf [accessed 15 May 2009]

Fountain, J. Patel, K. Buffin, J. (2007) Community Engagement: The Centre for Ethnicity and Health Model. In Domineg, D. Fountain, J. Schatz, E. Bröring, G (eds) *Overcoming Barriers: Migration, marginalisation and access to health services.* Amsterdam, Amsterdam Oecumenisch Centrum (AOMC)/Correlation network for social inclusion and health

Freire, P. (1972) *Pedagogy of the Oppressed* Harmondsworth: Penguin
Healthcare Commission (2007) Talking about medicines: the management of medicines in trusts providing mental health services [Available from www.healthcarecommission.org.uk Accessed 10.5.09]

Glasgow, Nicholas J., Jeon, Yun-Hee, Kraus, Stefan G., & Pearce-Brown, Carmen L. (2008) 'Optimising care for people with chronic disease, Chronic disease self-management support: the way forward for Australia', eMedical Journal of Australia, 189: 10 Suppl., S14-S16, via http://www.mja.com.au/public/issues/189_10_171108/gla10916_fm.html#0_i1092017 [accessed 10/05/09]

Grimmer-Somer, K., Guerin, M., Luker, J., Jones, D., & Zucco, M. (2009) 'Guiding principles for chronic disease management for vulnerable and disadvantaged people: pilot study findings', *The Internet Journal of Allied Health Sciences and Practice*, 7: 2

Hanifan, L. J. (1916) 'The rural school community center', *Annals of the American Academy of Political and Social Science*, 67, 130-138

Hanifan, L. J. (1920) *The Community Center*. Boston: Silver Burdett

Jordan, Osborne (2007) 'Chronic disease self-management education programs: challenges ahead', *MJA*, 186: 2, 84-87

Kit ,J, A. H., Prideaux, C., Harvey,P.W., Collins, J., Battersby, ,M., Mills, P. D. Dansie, S (2003) Chronic disease self-management in Aboriginal Communities: Towards a sustainable program of care in rural communities, Australian Journal of Primary Health 9(3) 168 – 176, 2003

Mountain, G. A. (2006) 'Self-management for people with early dementia: an exploration of concepts and supporting evidence', *Dementia*, 5: 3, 429-436

National Public Health Partnership (2001) 'Preventing Chronic Disease: A strategic Framework Background Paper'

Riessman, F. (1965) 'The "helper" therapy principle', *Social Work* (April 1965), 27-32

Seebohm, P., Henderson, P., Munn-Giddings, C., Thomas, P., & Yasmeen, S. (2005) *Together we will change: community development, mental health and diversity.* London

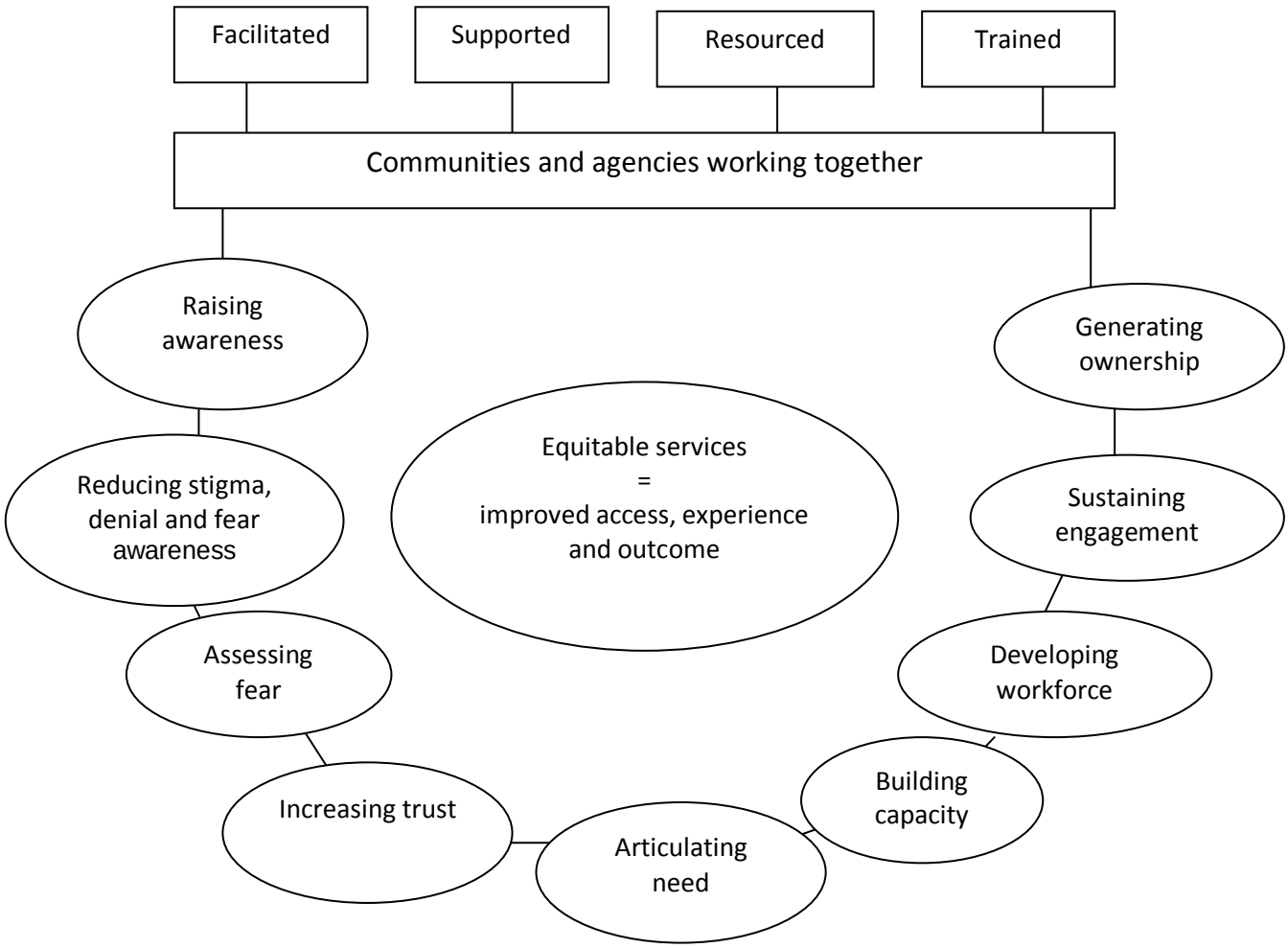
Social Action for Health (2006a) *Asthma UK Self Management Project Report* London

Social Action for Health (2006b), 'Social Welfare Advice in GP Practices: Evaluation Report', *Tower Hamlets Health and Advice Links Project* London

Wilkinson, R.G. (2005) *The Impact of Inequality: How to make sick societies healthier* Oxon & New York: Routledge

# Appendix 1 - Community Engagement Model

**Centre for Ethnicity and Health**
**Community Engagement Model**

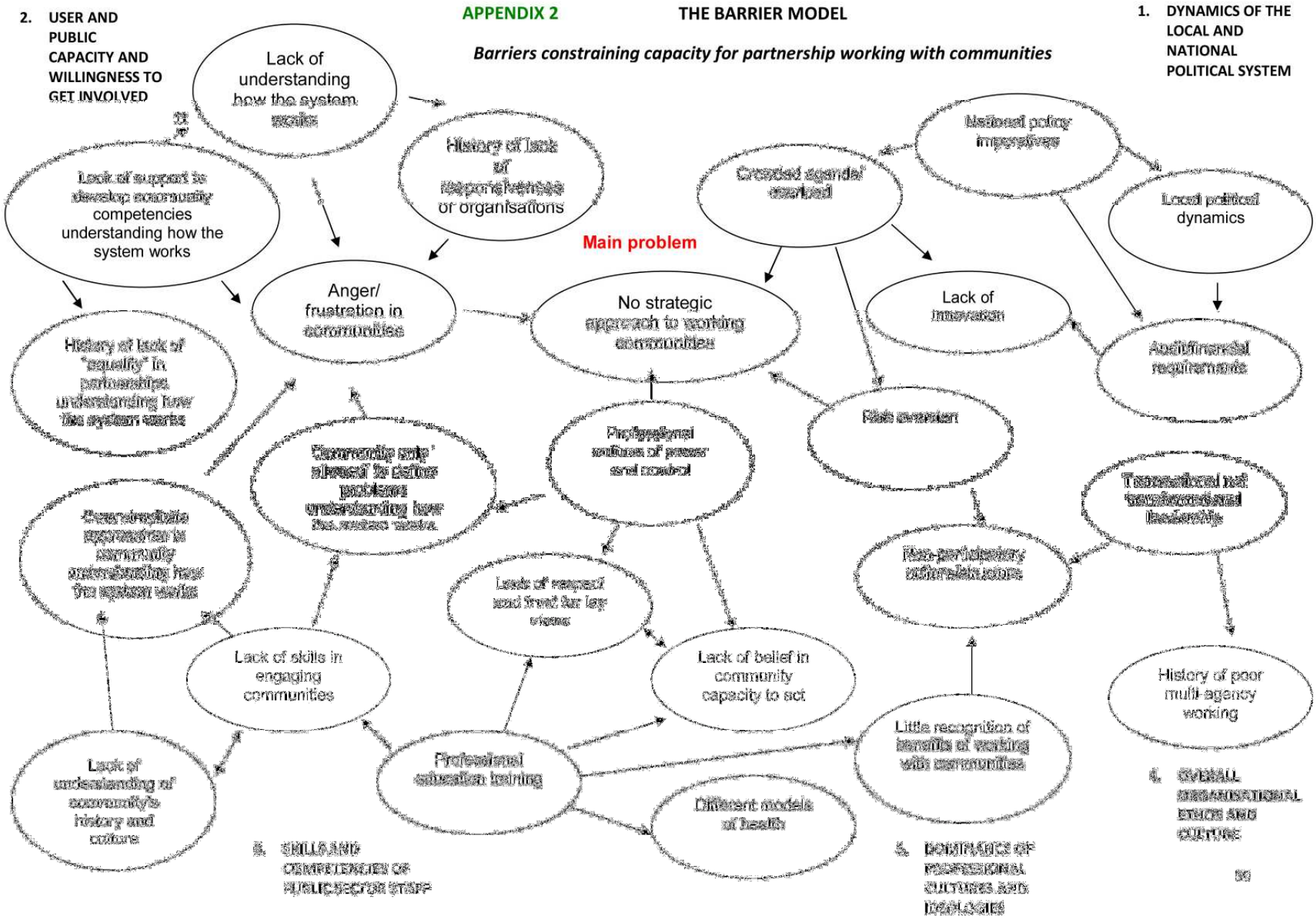


# Appendix 2 - The Barrier Model

See next page.

**APPENDIX 2** **THE BARRIER MODEL**

***Barriers constraining capacity for partnership working with communities***



# Appendix 3 – Focus Groups

## South West London – 14th May 2009

**What is working or has worked?**

| What has or is working? | Why? |
|---|---|
| **Experts Patients Programme** | Improves motivation and owned by the community, as reflected with CCH's Self Management Programme which offers further opportunity for peer support within community |
| Continuous contact – a face, name known to the community | Trust |
| Developing trust / community engagement good practice. Democratic, inclusive, facilitating partnerships | Not just parachuting in – build key relationships |
| **Co-creating Health** - Engaging service users / engaging primary care practitioners – partnership approach in training, using the patient and clinical expertise | Meaningful engagement with service users and carers through training |
| **Carers workshop** | Empowering carers – successful as targeted through an existing, trusted medium. Workshop was flexible to meet the needs and also didn't try and solve everything in one session |
| **Patient stories** and experiences - service user website (stories) | People given opportunity to tell their stories |
| **Bromley by Bow model** | Actually going into the community and making a number of services available in one location – not just healthcare – arts, health and housing. GP practice supporting local community.<br>Improved trust means group asking what the community needs to focus on. |
| **Community Development Project** (focused on housing estate in Kingston) | Community committee, being open minded about what communities needs and wants, and responding to those needs rather than being prescriptive. |
| **Happy Soul Festival** | Improving awareness of Mental Health in BME groups. Using art to engage communities and convey key messages. Culturally sensitive approach in cinemas, community centres etc – right language and approach |
| **Voicing Views** – working together conference for service users, carers, staff | Everyone had an equal voice and produced very clear action plans |
| **Somali Health promotion event** – 200+ attendees | Used food as a way to break down barriers with community groups. Full awareness of cultural differences, and translation / interpreter |
| **Merton Community** – New Directions team | Helping users navigate 'The System', and challenging agencies to work differently. Informing not prescribing. |

| | |
|---|---|
| **Intergenerational Identity and Wellbeing Project** | Responding to community request |
| **Process of mutual learning** | once one is open to learn, by modelling, all become at ease with the process of learning, therefore co-creating the new knowledge collectively and adding to each individual's tool kit. |

**What hasn't / isn't working well and why?**

| What's not working? | Why? |
|---|---|
| Engaging Korean population with mental health through a needs assessment to identify local priorities. | The community did not perceive mental health and well being in the same way the PCT did. Cultural beliefs and values not concordant. "We <u>had</u> to do it" – not the same as a priority. |
| Traveller community | Assumptions were made on beliefs and values / not shared priorities. This community's priority was to find schools for their children and health was not as important. |
| "Co-Creating Health" – clear understanding of what it means to service users and clinicians – the terminology used is not common language for users and clinicians | Need to use the right language, too much jargon. |
| Support of working with VSO's, where there are not inclusive or democratic procedures – results in broken trust / patronage / nepotism | Cautious! Need to have clear complaints procedures, and guidelines when working with VSO |
| Lack of joined up approach | |
| Lack of cultural sensitivity | Be open to ask, modelling, willing to learn |
| Communication | Clarity around expectations of CSMP (CCH) |

**The Future – what could work in the future & what would the potential obstacles be?**

| Future ideas |
|---|
| Building more co-ordinated relationships with community leaders. (Including refugee and asylum seekers) |
| Identify a 'pool' of community leaders and groups |
| More clarity about the use of language – specifically – what do we mean by engagement? (is it the same as involvement / consulting / gaining buy –in etc) |
| Improve training the communities in Self Management programmes |
| Use the health trainer model to deliver advice and help in self care for communities: potentially voluntarily or funded approach |
| Build collaborative networks with decision makers – empowering them and enabling them to engage |
| Improved / increased engagement with existing Voluntary Community Faith Sector (VCFS) organisations, and providing the right infrastructure to allow this to happen |
| Provide funding to allow engagement from the 'bottom up' |
| More Community Development Workers (CDW) |
| Have Culturally appropriate programme trainers |
| Engaging Asian women – historically a difficult to access group – provide opportunity to build trust and rapport in a non-healthcare / non threatening environment |
| Developing a generic model for self management to support people with co-morbidities - one stop shop for community support |
| Public large scale well being events – potentially covering many services / health areas |
| Workplace well being interventions |

| |
|---|
| Opportunistic opportunities for communities to engage with self care – e.g. exercise bikes in the playground; piggy backing on other, existing events – reducing stigma? |
| Engagement of colleagues – building a culture of positive change instead of apathy / indifference |
| Main future idea – Co-ordination between all sections – health / community, social |
| Increased use of low intensity workers |
| One clear model that can be adapted to cultural / situational needs |

| **Potential Obstacles:** |
|---|
| Lack of decision maker buy-in |
| Lack of joined up working |
| Fear! (of change) |
| Ideas and concepts are too big to grasp, and default behaviour is to stay with what we know |
| What's in it for Me? – Either the individual, the organisation, the community – why should I do this? Potential capacity / knowledge / resourcing issues. Cost benefit for employers |
| Variety of cultures – difficult to engage and co-ordinate |
| No funding into communities – tokenism |
| Current bureaucratic systems |
| Uncertainty of individuals around the benefits of engaging or improving self care – possible stigmatism of attending events / groups etc |
| Privacy, language and cultural stereotypes |
| Co-ordination of different agendas and time constraints |
| Possible formation of health ghettos |
| Motivation, condition agency stereotypes |

## Whittington Hospital - Focus Group Summary

**What is working or has worked?**

| What has or is working? | Why? |
|---|---|
| **Co creating health model** – lay and HCP on same level | Mutual respect – non hierarchical |
| **Improving Reach Programme -** Islington. Supporting the forums for faiths, BME and refugee workers | Brought the 3 forums together and worked as a partnership |
| **EPP** | Supporting self management of people with long term conditions |
| **"Hands Up"** deaf consultation - Islington. | Organised and led by the deaf community and supported by statutory partners (LA / NHS) |
| **Care coordination** – across health and social care one professional taking responsibility | Reduces duplication and need for face to face contact |
| MDT approach | More efficient |
| Local involvement networks – LiNKs – Islington | Supported by local VSO (IVAC); agenda set by the network |
| Personalised approach | Respiratory team = Behavioural change |
| **School packed lunch events** - programmes for schools – | Family approach - health eating message adopted by children and parents |
| **Cook and Eat** - for weight management groups | Practical hands on demonstration supported learning and adoption of new cooking techniques; interactive |
| **DESMOND** for type 2 diabetes | 6 hour (usually 2 x 3 hrs) Diabetes education programme in a community setting. Run by health care professionals |
| **Improving access to palliative care** – focus groups with GPs, carers and patients. | Primary care, secondary care and hospice working together – community based and services being delivered by own culture. Patients and carers giving direct experience of what works well and what barriers are and helping to identify how to improve services and access. Willingness to speak in the language that the person can relate to and understand fully |
| **Improving cancer services** | Individual interviews with patients and carers which identified other issues e.g. need for financial support.<br>Willingness to listen to people's needs |
| **Social marketing approaches** – targeting and segmentation | |
| Supporting people to manage their chronic respiratory symptoms more effectively | Reduce the stigma people feel about this illness (using first language) |
| **Breathe easy** group - willing to support others and improve awareness of chronic respiratory diseases. Supported by British Lung Foundation and local community respiratory specialists | Patient led – people are sometimes unwilling or unable to listen or change |
| **Training of Community Nutritional** | With their level of knowledge and education, |

| | |
|---|---|
| **Assistants** (CNA) | can educate people in their local community with non-complicated issues (e.g. weight management) |
| **Diabetes Day** | Well attended - potentially combining with another generic event can reduce the stigma of attending (conversely – people know if they ar attending a Diabetes event – then they will be able to get specific help for their issues |
| Different approaches /tools | Personalisation and giving choice |

**What hasn't / isn't working well and why?**

| What's not working? | Why? |
|---|---|
| Information days – where people are made aware of what support and information is available to them | Poor marketing / communications. Poor location (HOWEVER, these events can be successful as well) |
| Links with voluntary sector | Need to have closer links |

**The Future – what could work in the future & what would the potential obstacles be?**

| Future ideas |
|---|
| There needs to be an improved level of trust between people and the health care professionals, and provide a more flexible service to meet the needs of individuals |
| Self Care should be "made to matter" to GPs - whether financially, morally or otherwise. GPs should be more accountable to drive Self Care, and we should stop "pussy footing" around them. |
| Should be more 'shared' responsibilities between HCP and people – joined up interactions / structures |
| More marketing of the concept of self care – more public awareness |
| Health workers to develop more community development skills and Community workers to develop more supporting self management skills. |
| Self care should be delivered by someone from their own community (peer led) |
| Improved maintenance plans to support self management (ongoing schedule for contact – not a one hit) |
| Plain and clear communication – right level / language / often enough in the right places |
| Buddy system |
| Improve support so people know where to go for information |
| Increased use of the voluntary sector |
| Use innovation / technology – e.g. text updates / Facebook and social networking sites |
| Use appropriate and varied locations for delivery in the community e.g. libraries for the older generation |
| Take more of the work out in to the communities rather than expecting people to come into the health care settings |
| Challenge the thinking about who is the 'professional' |
| Work jointly with social care partners |
| All health and social care professionals trained in understanding what self care / management means and what needs to be in place |
| Run these type of focus groups out in the communities |
| Key to define what we mean by communities: are they ethnic groups, community groups, groups joined by disease area etc. Once defined, should then highlight the "unreached" communities as a priority and formulate plans to reach them specifically |
| Using NHS Trust membership - Share messages with local communities (currently have 4500 members at Whittington) |

| **Potential Obstacles:** |
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| Hierarchy within the healthcare profession and the way in which patients are viewed |
| Lack of trust and using loopholes in the system to avoid taking responsibility for supporting self care. |
| Language and culture |
| Time, money and general apathy |
| Recruitment of appropriate people to deliver and drive self care agenda |
| It may be impossible to 'force' a cultural change (with incentives etc) – needs to be led from a strategic level |