



COMMON GROUNDS?

**Building Alliances for Positive
Mental Health: Communities,
Community Development and
Service User Groups**

21st July 2008

CONFERENCE REPORT

Centre of Excellence in Interdisciplinary
Mental Health

University of Birmingham

A Joint CEIMH/FCDL Event

CEIMH

Centre of Excellence in Interdisciplinary Mental Health



supporting communities
creating change

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BUILDING ALLIANCES FOR POSITIVE MENTAL HEALTH
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1. Introduction: About This Event

Why ‘Common Grounds?’

Over the past 20 years there has been a growing mental health service user and survivor movement. During the same period community development policy and practice has changed rapidly. Yet few connections have been made between user groups, community organisations and community development work. Indeed, the policy perception that ‘involvement is good for you’ has rarely been questioned – either in terms of promoting positive mental health, service change and community regeneration.

The aims of this one day conference, organised by the Centre of Excellence in Interdisciplinary Mental Health (University of Birmingham) in partnership with the Federation for Community Development learning were to::

- examine common ground between service user movements, community groups and community development practitioners in terms of values and objectives and the issues they face
- question current involvement and engagement agendas in health and community settings from a range of grass roots perspectives
- identify the potential for sharing good practice, developing learning opportunities and influencing service developments in communities and in mental health provision.

The conference was a pilot event which, as such, also explored possibilities for future joint work between those active in communities and those involved in promoting service user participation.

For more information and video materials on the aims and outcomes of the event [click here](#).

This event was attended by 45 participants who were:

- mental health service user activists
- community development practitioners
- people involved in community organisations
- health involvement and participation workers
- those involved in mental health service development and planning
- agencies involved in promoting community engagement and public participation.

‘Common Grounds?’ discussions fell into two parts. Firstly, the morning sessions explored the question: were there common issues - in terms of policy, values and

goals - between service user groups, community activists and professional community development/health participation workers? Were there also key differences? Secondly, the afternoon session examined practical examples of community development and user involvement in making a positive contribution to mental health – and how/whether any shared agendas could be taken forward in practical ways. In addition, participants had the opportunity to record [short videos](#) about the themes of the day and their reflections.

At the outset, participants hopes for the event were that it would:

- *“Bring together the worlds of communities and service user groups”*
- *“Help us bridge the gap between the services and real needs in communities.”*
- *“Build a greater understanding of the potential for joint work between community development workers and service user groups.”*

We hope the current report represents both an accurate record of presentations and discussions on the day and offers some practical suggestions for building ‘common grounds’ between community activists, development workers and those involved in service user movements and building the user voice in mental health care planning, delivery and evaluation.

Acknowledgments

Thanks to The Centre of Excellence in Interdisciplinary Mental Health for funding and hosting this event – and to the Federation for Community Development Learning which contributed to both the planning and delivery of ‘Common Grounds?’ Our appreciation also to all the contributors – who offered their time and expertise free of charge - and to participants, from a wide range of backgrounds who contributed to the quality of discussion on the day as well as video materials – and offered practical suggestions for taking forward future joint areas of work.

‘Common Grounds?’ was heavily oversubscribed – with some 250 applicants for just over 40 available places. This reflects both the interest in the topic and the need for further shared learning opportunities. Our apologies to all those who applied to attend – but could not be accommodated.

2. Keynote Presentation

The Fundamentals of Communities, Health and Wellbeing: *Prof. Ann Davis*

Professor Ann Davis, Director, Centre of Excellence in Interdisciplinary Mental Health, University of Birmingham, welcomed participants and provided an overview of the contexts which had informed the development of the 'Common Grounds?' event.

Orientation to work in this area

As community development workers, activists or service users we all work with mental health, because:

- It is well established that the poverty, deprivation and social exclusion which characterise disadvantaged communities are both causes and consequences of mental distress and mental ill health.(ODPM:2004)
- The major concerns identified by people living in disadvantaged communities are the same as those identified by users of mental health services- income, debt, employment, housing, environment, transport, crime, personal and family relationships. All require action as well as access to a range of appropriate responses. (Repper and Perkins:2003)

Developing good practice

Good practice in community development work delivers on the approaches that people with mental health issues in their lives value. Because it responds to people's pressing concerns, treats them as experts in their own lives and supports them to actively gain a sense of self worth, control, participation and skill acquisition.

But there are some major issues that we need to recognise and address in considering the common ground between community development and user oriented activities in the mental health field:

- Mental health services and practices are still dominated by individualising medical approaches that locate issues within individuals and seeks change in their behaviours rather than recognising the social context of people's distress and behaviour.
- The stigma and discrimination attaching to issues of mental ill health is profound. They are embedded in general attitudes, understandings and responses as well as service provision. This needs to be recognised, understood and worked with

- Mental health is as an issue for us all i.e. community development workers as well as people living in deprived communities and this needs to be worked with in relation to how we organise our work.

It is important to understand the way in which diagnostic services and mental health service provision can create excluded communities of service users which strip people of their citizenship, community membership and confidence in themselves.

Practice orientation

In working through these issues it is helpful to be oriented by Standard One of the National Service Framework for Mental Health [NSF]:

“mental health for all, and working with individuals and communities to combat discrimination against individuals and groups with mental health problems and promote their social inclusion” [DoH:1999]

This provides a recognised focus to work in this area which gives full recognition to the potential contribution of community development approaches to promoting mental health and well being and delivering on mental health agendas.

To deliver fully on this involves mutual learning about mental ill health as well as effective community development work. It also involves working in ways that take full account of the need to promote the mental wellbeing of all involved, individually and organisationally. There are no ‘them’ and ‘us’ - all of us are vulnerable to emotional and mental distress.

Useful References

Department of Health (1999) *National Service Framework for Mental Health*. London, DoH

Office of the Deputy Prime Minister (2004) *Mental Health and Social Exclusion*. London, ODPM

Repper, J. and Perkins, R (2003) *Social Inclusion and Recovery: A Model for Mental Health Practice*. London, Bailliere Tindall

3. Community Development: Principles, Issues, Policy and Practice: *Janice Marks, Federation for Community Development Learning*

Janice Marks, Head of Agency, Federation for Community Development Learning, presented an overview of community development principles, policy and practice in a rapidly changing environment.

The Purpose, Values and Role of Community Development

The key purpose of community development, as outlined in the occupational standards for the field is to collectively bring about social change and justice, by working with communities to:

- Identify their needs, opportunities, rights and responsibilities
- Plan, organise and take action
- Evaluate the effectiveness and impact of the action.

All this should take place in ways that challenge oppression and tackle inequalities and is informed by the key values of:

- Social justice
- Self-determination
- Working and learning together
- Developing working relationships with communities and organisations.

The key roles played by community development workers include:

- Encouraging people to work with and learn from each other
- Working with people in communities to plan for change and take collective action
- Working with people to develop and use frameworks for evaluation
- Developing community organisations
- Working for sustainable communities
- Participation
- Reflective Practice

Current Issues in Community Development

References to community development, or community development approaches appear in all kinds of policy documents and initiatives. It is there in the sustainable communities agenda. It is there in The Local Government Act (2007) – with its emphasis on devolving powers to Local Authorities and they in turn, devolving decision making to the neighbourhood or community level. It is there in all the major regeneration



initiatives of the last decade. From City Challenge through to the Single Regeneration Budget and on into The Neighbourhood Renewal Fund and New Deal for Communities. It is in all the modernising government white papers and in the service improvement agenda within the NHS.

So, in a very real sense – it's everywhere and nowhere.....

Why do we say this – that it is nowhere? It may have seemed strange to start this presentation, at an event for those involved in community participation – either in mental health services or in neighbourhoods – with a reminder of the principles and values which underpin community development. Many now active in the field come from very different backgrounds and they – and/or their managers – appear to be unaware of the occupational standards. Accordingly there are those – they may be called liaison workers, development workers, participation officers – who are 'doing community development' whilst lacking an understanding of its core values, principles and roles. Certainly, official policy statements – whether from central or local government – do not reference what is absolutely key to community development – enabling people to take collective action to challenge oppression.

Further, routes to qualification – whether in health or social care settings – make little reference either to ideas of community or community development as a model of working. For practitioners, opportunities for continuing professional development are limited.

Community development is also a long term process. This has been recognised in reports such as 'The Community Development Challenge' (Communities and Local Government: 2006). Yet all too often it relies on short term – project specific – funding. So in communities, in health settings, there is often a start/stop pattern for community development and participation work. This can be a damaging process for all involved. Funding is for such a short period that it is difficult to demonstrate positive outcomes – so community development is seen to have failed. Activists,

service users become enthused – but then lack support and all too often become over-burdened and burn out.

In the current climate – where the importance of participation is acknowledged in the language – if not in what actually happens ‘on the ground’ – there are some very real challenges and questions for community development:

- How do we support managers and workers who aren’t community development workers to work more effectively with community groups and communities ?
- Community development is based on people identifying their own needs and agendas for change – how does this relate to procurement agendas, competitive tendering, service delivery and funding opportunities based on prescribed outcomes?
- How do we challenge the current ‘top down’- rather than ‘bottom up’ - model of communities and community development?

I am not saying these are all the key issues – just some of them. The term community development is used very liberally – sometimes to cover anything that takes place in the community, whether empowering and value based or disempowering and tick box based. So the real challenge is - how do we support and promote good quality community development work and demonstrate its value and outcomes?

Useful References

Communities and Local Government (2006) *The Community Development Challenge*. CLG, London

To view the Community Development Occupational Standards, visit <http://www.fcdl.org.uk/publications/index.htm#StandardsSummary>

4. Service User Movements: Principles, Issues, Policy and Practice: *Tony Kirk and Angela Hill, Users in Partnership*

Tony Kirk and Angela Hill from Users in Partnership presented an overview of the work of UIP and the challenges faced in developing user voices in mental health care service planning, delivery and evaluation.

About Users in Partnership (UIP)

UIP was formed over 12 years ago by a group of service users who wished their voices to be heard in mental health decision making processes. (This was in the days before it was common to have user groups or involvement workers) Their case was taken up by West Midlands Partnership in Mental Health.

For a number of years the organisation was hosted by the National Institute for Mental Health in England, the mental health arm of the Care Services Improvement Partnership. In 2006 the membership decided to become independent, and in 2007 the organisation became registered as a Community Interest Company.

We now have a database of members throughout the West Midlands with a wide range of experience and expertise, including Users and Carers and allied workers. Our members cover the geographical diversity of the area from inner city to rural countryside. We also work closely with our sister organisation Carers in Partnership and have worked with a broad range of organisations over the years, including Universities, mental health charities NHS Trusts and national bodies such as the Care Services Improvement Partnership.

What we offer to commissioners of services:

Our experienced membership can be called upon to give training in Mental Health awareness to staff and we also offer:

- user-led audit of services including 'mystery shopper'.
- help to organisations to fulfil their obligations under the 'Health and Social Care Act 2001' which places a duty on organisations to consult with users and carers in service design and provision.
- Peer support for existing user development/involvement workers and links for them into regional and national groups.
- translation of key health policies and documents into 'user friendly' formats.
- trained interviewers for recruitment panels where it might be inappropriate to use local members or groups.

What we offer to individual service users:

- network meetings throughout the West Midlands where individuals can meet with like-minded people
- opportunities to access training courses tailored to individual needs and to give training sessions to other members, groups and stakeholders
- information on how to lobby for improved Mental Health and Social Care Services
- access to our database of services in the West Midlands, a valuable signposting and information facility
- assorted opportunities for voluntary work including website design and office experience
- up to date information on mental health issues.
- a collective voice to influence policy.

Some of our members also sit on Local Implementation Team (LIT) and Partnership Boards and are offered appropriate support

What we offer to user development workers:

- methods of sharing good practice of service improvement.
- access to training
- access to a database of services, groups throughout the West Midlands.
- networking opportunities with regional and national colleagues
- support and advice when initiating user – led projects.

Some Principles and Issues

UIP is a well established organisation, with strong local/regional networks offering a range of services to different stakeholders in the field of mental health. We strongly believe that service users can bring about changes and improvements in mental health services when they:

- can work together in groups and develop a collective – and more representative – voice
- have access to training, support and information which enables them to be more effective in representing needs to service providers and policy makers
- have access to networks which overcome the sense of isolation often felt by user activists
- are involved in regional, and ideally national, initiatives and networks which facilitate the sharing of ideas and identifying areas of good practice which can be learned from and applied elsewhere as well as developing shared ideas and strategies for overcoming barriers to change.

UIP is, however, working in a rapidly changing environment. This has raised a number of issues for us recently as we work through a period of uncertainty – not only for ourselves, but for the wider user movement. The following list is not exhaustive, but gives a flavour of some of the challenges faced:

- as a Community Interest Company (CIC), we are encouraged to act as entrepreneurs. These are very different skills to those required to run a regional network organisation which has had a fairly stable funding base. Not all of us want to be entrepreneurs! What interests us is delivering the services that form our core purpose of supporting service user groups and influencing policy and practice.
- being a CIC potentially changes the relationship with other groups. Those that may have been partners can become competitors for the same resources
- professionals get opportunities to network. This is just as important for service users and groups – but the value of networking is not recognised in funding streams which are about achieving ‘measurable outputs’
- training and support to enable user groups to be effective is vital. Again this is not always recognised by the Trusts. It is almost as if you can become a fully fledged activist, or ‘expert patient’ on your own
- individual Trusts are reluctant to pay for services that operate on a regional basis and across Trust boundaries. Groups like UIP fulfil a regional role that no-one wants to finance – and we do not have the capacity to negotiate contracts with all the individual Trusts across the West Midlands
- one positive development is the recognition by Universities, Colleges and others that service user input on recruitment, training and evaluation programmes needs to be paid for. What they pay for though is the individual involved – and not the networks which support them and becoming a membership funded organisation at a regional level is not particularly viable – given the social exclusion faced by many current and potential members.

Finally, UIP is an independent organisation. There is a question mark here. Will commissioners continue to support groups such as ours when they are required to



go through ‘officially sanctioned’ consultative structures such as Local Involvement Networks? Yet what are the implications for service user groups – and for health services themselves – if ‘independent voices’ are lost? So the big issue is about how to sustain independence – and secure funding which both respects that independence and recognises that building user voices is a long term process which should not, cannot, be sustained through short term (and competitive) contracting.

5. Workshop Report

Identifying Common Grounds: Communities, Community Development and Mental Health Service User Movements

Following key not presentations on principles, policy and issues in the fields of service user engagement and community development, participants broke into discussion groups to:

- reflect on the key themes from presentations
- explore both common grounds – and differences between – those active in communities/community development practice and service user movements and health participation workers.

The main points from workshop discussions were:

- The language is different – but there are clear links between service user involvement and community development. Service users talk of recovery – community workers about regeneration for example. But a shared principle is one of promoting self determination. Also, workers in different settings address the stigma of:
 - mental distress
 - living in a particular neighbourhoodbut the issue of stigma and discrimination is a shared one.
- There may be common grounds between mental health service user movements and community development work – but there are very few opportunities to share experiences, learning and ideas.
- Much more needs to be done to:
 - raise the awareness of health staff about how service users can become active in their communities and in public life
 - ensure that community development workers have a better understanding of mental distress and can address this more effectively in the groups they are working with.
- Also, it is dangerous to ‘separate out’ community activists/service users and professionals. Professionals may also live in communities facing difficulties. They too may experience mental distress.
- Often the focus is on the negative – both in terms of communities and mental health. There are examples of good practice out there. Examples of where

people's active involvement has brought about change. We need to share those more – and build on them.

- Whether in mental health or communities – change can be a frightening process. More needs to be done to support people through change.
- Taking a holistic approach is vital. It is all about addressing those things that affect peoples' lives – not putting mental health '*in its own little box*'
- Community organisations and service users can be an effective bridge between services and the community and vice-versa. This role of acting as a broker between groups and services is important, but its value is not recognised. Groups keep being pushed into delivering services – not advocacy and support.
- How do we address the real fear of mental health issues in communities – particularly Black and Minority Ethnic/Refugee communities? Are there ways that service user groups and community development workers can learn together to address issues of fear and stigma?
- The jargon gets in the way in both community development and mental health. Are we not really talking about peoples' well being and happiness?

“There may be ‘common grounds’ between service user groups and community development. But there are also real differences. In some ways these are artificial. Funding is often target driven and service specific. As a mental health (participation) worker, I cannot say, oh, I’m working with all these community groups when my performance is judged on the number of people involved in mental health trust consultation events. I suspect that is true for community workers too. You can’t say I’m doing all this stuff around mental health when what the funder wants is more people active in resident’s groups or whatever.”

6. Presentations

The afternoon session consisted of three presentations:

- Building Accepting Communities: working with mental health: *Sonia Thompson and Angus McCabe*
- Creating Change: from activist to worker or entrepreneur? *Patience Seebohm and Dr. Val Harris*
- Community Organisations for Mental Health; The Refugee Experience: *Saeed Abdi*

These aimed to have a practical focus on what can be learned about the similarities (or 'common grounds') between community development and service user involvement and identify what we are learning from current practice in both health and community settings.

This leads to discussions in workshops and a final plenary on ways forward in building alliances for positive mental health.



Presentation:

Building Accepting Communities: working with mental health: *Sonia Thompson and Angus McCabe*

Are there common grounds between community development practice in community and mental health settings?

Community Development Perspectives	Community Development and Service User Groups
Community engagement is a cornerstone of Government policy - active citizenship and regeneration.	Community development is viewed as a key tool for promoting mental health service user involvement.

As previous speakers have noted, community development has become a key element of a wide range of government policies in both regeneration and health service improvement agendas. There has been some investment in a variety of mechanisms for community and service user ‘engagement’ – from expert patient panels through to citizen juries and neighbourhood forums. What is not always clear is what is meant by engagement. Is it participation in the true sense of the word – with communities and service users as equal partners? Is it ‘involvement’ – on an ‘as and when’ basis – depending on whether the ‘engagement’ box has to be ticked in a particular initiative? Or is it only consultation and information giving?

All too often, in both regeneration and mental health settings community development is seen as a ‘box of tricks’ that will get people out to a meeting/event – rather than a longer term change process.

Community Development Perspectives	Community Development and Service User Groups
‘Community engagement’ is seen as good for the health of individuals and communities - improving outcomes for communities	User involvement has been linked to service improvements and better health outcomes for service users.

When we look at the literature and policies on community development and user involvement – it is almost universally seen as ‘a good thing’ and ‘good for people’. If we look at the quotations in the handout (overleaf) – they are all positive and hard to disagree with. But equally – it is not always clear what the statements actually mean in practice. Only one quote – interestingly, from Hazel Blears M.P. – confronts the

hard issue in community development – the imbalance of power that exists between agencies/professionals and community activists/service users.

Community Development Perspectives	Community Development and Service User Groups
Community activists as 'experts through experience' - empowering individuals and groups	Service users as 'experts through experience' - empowering individuals and groups

This means

- Involving individuals in their own care and treatment – e.g. there are now publications on writing your own care plans (Leader 1995) and
- Involving groups/organisations set up by and run by people who have used the service – giving feedback on the way the service is being experienced and influencing policies and practices

It also means involving people

- Not just when a major change is proposed, but in ongoing service planning
- Not just in the consideration of a proposal, but in the development of that proposal; and
- In decisions about general service delivery, not just major changes.

Department of Health and Care Services Improvement Partnership: Reward and Recognition – The principles and practice of service user payment and reimbursement in health and social care – A guide for service providers, service users and carers: contact – www.dh.gov.uk/publications . Involvement of service users is a central element of health and social care activity.

The NHS is required to consult and involve service users under Section 11 of the Health and Social Care Act 2001. Good practice for CDWs in Black and Minority Ethnic communities calls for the allocation of a budget in every programme to support service user involvement.

It is also important to acknowledge that ‘experts’ can be exclusive and oppress dissenting voices. It is therefore important that community activists/service users as experts can challenge professionals – and vice-versa. Resources are needed not only to involve individuals and groups in communities and mental health – but also to ensure that they have the resources to report back to, and be held to account by, a wider constituency.

Community Development Perspectives	Community Development and Service User Groups
Being a community activist can damage your health!	Can user involvement – keep people 'locked in the mental health system' and prevent recovery?

To what extent can activism including user involvement tie you down and restrict your identity? Does the label precede you? Do you find that you are only called upon to respond to issues concerning mental health and not on broader community development issues? Is this a problem?

Does this type of labelling impact on how we see ourselves?

Is user involvement work draining to the extent that it can impact on your health? How often have we seen community/service user activists 'burn out' or risk their own relationships and safety because they are always out at meetings/never have time for the kids etc. etc?

How many service users do we know for whom 'stopping being involved' was a crucial part of [recovery](#)?

Is there a time limit to which someone can work in the field of mental health user involvement/community activism and remain healthy? People often become activists because they are angry – about the quality of a service or the treatment of their community. How long can anyone remain angry? Is anger recognised or addressed as a legitimate reason for being involved by the professionals?

Community Development Perspectives	Community Development and Service User Groups
Community Development Workers feel unable to address mental health issues in the community/in community groups. Fears of 'the mad'?	Connecting user involvement networks and community development networks is important – but do communities accept service users?

A key role of community development is to support individuals and enable groups to function effectively. Often, however, we lack the skills or confidence to address issues of mental distress in the activists we work with. Often mental health is an issue to be avoided – or resolved when an activist burns out and just leaves a group.

Mental health service users are encouraged to take an active role in the communities where they live. Yet community groups may not accept service users – or actively label and exclude them. Do community participation workers have the skills and knowledge to address negative attitudes to mental distress in the community?

Developing networks between mental health service users and community workers/activists might be one way of beginning to address these issues – but:

- How big are your networks? Could they be bigger? Would it be useful if they were?
- What might be the benefits of having wider networks?
- What are the values and skills in community development and how do they relate to user involvement skills and values?

Community Development Perspectives	Community Development and Service User Groups
The agenda for community engagement is controlled by Government policy agendas - engagement on our terms?	Service user involvement funded by Mental Health Trusts - involvement on their terms only?

In this morning's session, Janice Marks has already commented that "*community development is everywhere – and no-where.*" The real question for community development/participation workers (whether in neighbourhoods or mental health settings) is – who sets and controls the agenda? Is it a genuine partnership between stakeholders – or do the professionals hold all the power?

Questions

- Are these issues real for participants?
- Community activists and service users - addressing issues of power?
- Strategies for linking community development agendas - health, regeneration and 'active citizenship'?

PRESENTATION HANDOUT

Building Accepting Communities: Working with Mental Health

Sonia Thompson and Angus McCabe

KEY POLICY STATEMENTS AND QUOTATIONS: FOR CONSIDERATION

Neighbourliness + Empowerment = WELLBEING: Is there a formula for happy communities?

While economic output has nearly doubled in the last 30 years, there has been no corresponding increase in happiness. With the wellbeing agenda firmly on central and local government's radar, this timely report from the Local Wellbeing Project highlights the practical ways that community and neighbourhood empowerment can influence the wellbeing of residents and communities, which can be as simple as getting to know your neighbours or getting involved in improving a local park.

According to Lucy de Groot, executive director at the IDeA, *"Local government and other public bodies often control issues and services that affect the quality of life of local residents. People feel very strongly about things, like local crime, green spaces, and leisure facilities, but a lot of the time they are beyond their control. Service providers need to work with local people to involve them in the community – and this report shows the effect initiatives can have on wellbeing. Relatively simple ideas – like street parties, suggestion and awards schemes, can have a surprisingly strong impact."*

(Young Foundation Report: 2008 – Mandeep Hothi et al)

EMPOWERMENT

Working in ways which are:

Confident – increase people's skills, knowledge and confidence and instil in them the belief that they can make a change

Inclusive – recognise that discrimination exists, promote equality of opportunity and good relations between groups and challenge inequality and exclusion

Organised and co-operative – bring together people/build positive relationships across groups around common issues and concerns in organisations that are open, democratic and accountable

Influential – equip communities to influence decisions, services and activities

Jill Bedford: Changes – in *"Empowering evaluation: evaluating empowerment"*; Community Development Exchange; 2008

“People should have the maximum influence, control and ownership over the decisions, forces and agencies which shape their lives and environments is the essence of democracy. There are few ideas more powerful, or more challenging. People with power are seldom willing to give it up readily; people without power are seldom content to remain enslaved.”

(Hazel Blears MP; Introduction to: *Communities in Control*; Communities and Local Government: 2008)

‘Strengthening informal networks helps communities to become more integrated, and provides individuals with the links they need to find support from friends and neighbours, and to access services.

It also creates the foundation for communities to organise themselves collectively into self-help groups or voluntary organisations either to provide support services directly or to put pressure on the statutory services to become more appropriate to their issues and diverse cultures.’

DoH - Mental Health Policy Implementation Guide

Community Development Workers for Black and Minority Ethnic Communities

‘We were told that it reduces the risk of providing unsuitable or inappropriate services, as users will often be in the best position to judge their own needs. In addition, user involvement can encourage people to better understand their own service needs and improve their confidence. This, in turn, can have positive effects on the outcomes they want to see, such as improved health or educational progress.....There are many advantages claimed for user-driven public services, including strengthening citizenship and improving public services. An evaluative evidence base is starting to emerge, indicating that user-oriented services have resulted in higher satisfaction with services and better outcomes.’

House of Commons Public Administration Select Committee User Involvement in Public Services Sixth Report of Session 2007–08 Ordered by The House of Commons to be printed 24 April 2008

‘Perhaps, therefore assumptions were made that, as a patient, I was informed, involved and empowered but like most assumptions they can be, at least, misleading and often wrong. I felt ‘done to’ rather than included as a partner in my care..... Professor Phil Barker asserts that in the process of healing in mental health, the patient does most of the work (Barker, 1997)....My belief in recovery was sparked, not in high-blown consultation, but by the kind, respectful ordinariness of a unit cleaner who saw me as a person, not an illness and communicated with an uncomplicated compassion that was in stark contrast to my experiences with many professionals. Once belief was there then the faltering process of healing could begin.’

Bill Davidson: User Involvement Lead, National Workforce Programme/New Ways of Working Research Associate, King's College London, University of Wales Swansea
Patient Consultant, Royal College of Nursing, Leadership Programme

Useful References

Barker, P. (1997) *Assessment in psychiatric nursing – in search of the whole person*. Stanley Thornes, Cheltenham

Seebohm, P. & Gilchrist, A. (2008) *Connect and Include: An exploratory study of community development and mental health*. National Social Inclusion Programme/National Institute for Mental Health in England, London

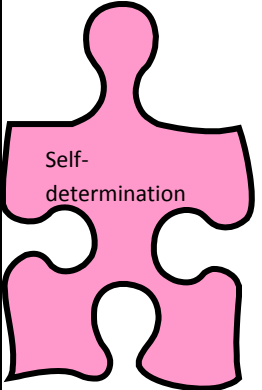
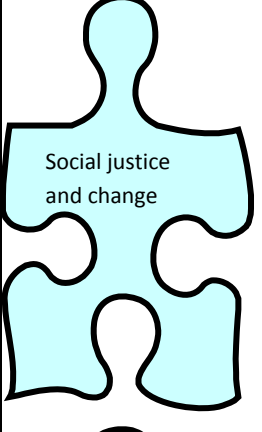
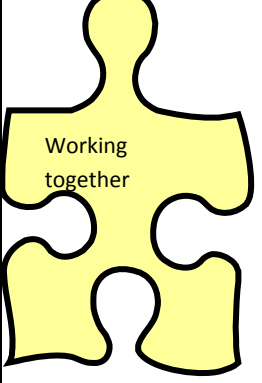
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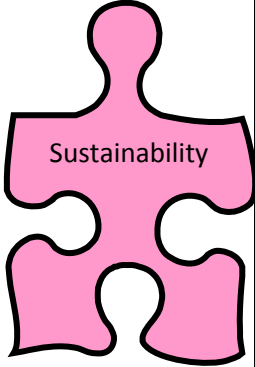
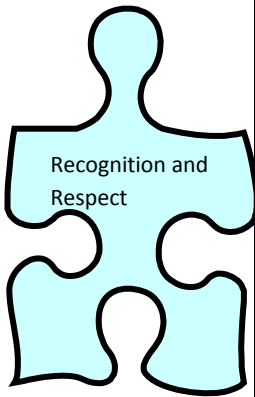
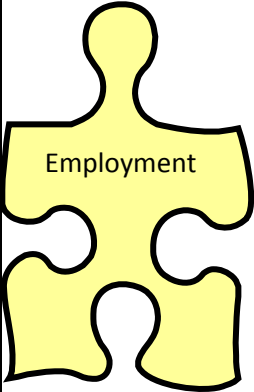


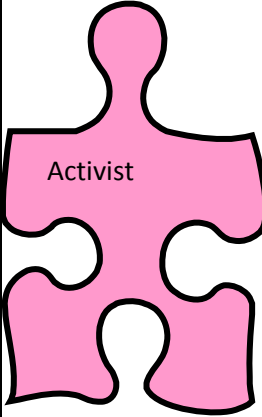
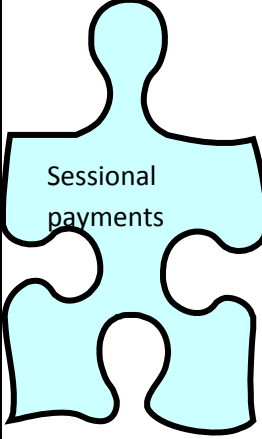

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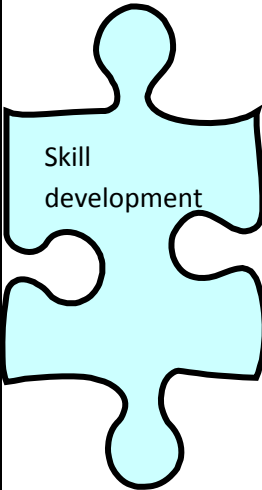
Creating Change: from activist to worker or entrepreneur: *Patience Seebohm and Dr.Val Harris*

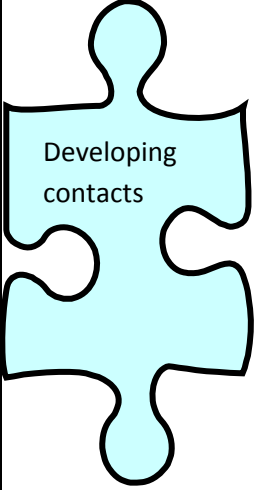
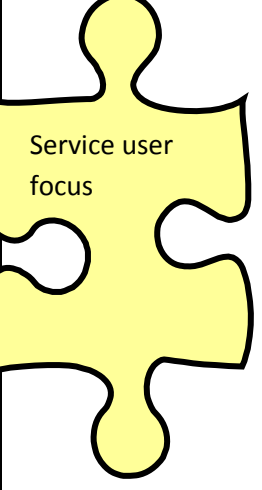
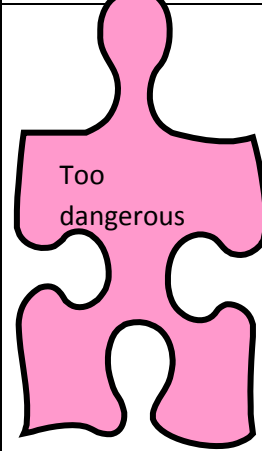
This session reflected on practice issues in service user movements and community development – exploring in particular the transitions from activist to worker – or entrepreneur.

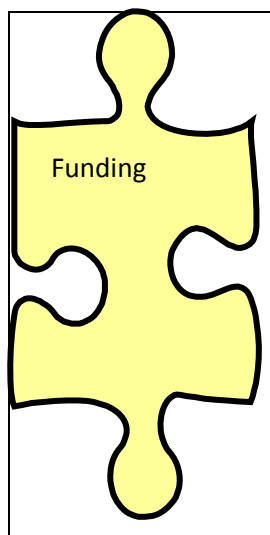
Key words	Mental Health: Service User Perspectives	Community Development Perspectives
Slide 1		
	<p>During a period of crisis in mental health, control over your life can be taken away. When people start to feel better, they want to take that control back, to make things happen.</p>	<p>People want to have influence over decisions affecting their communities.</p> <p>One of the key principles behind CDW is for communities to define their own problems and work out solutions.</p>
	<p>People with direct experience of mental health know that they can do many things better than others – like training, research and providing support to others.</p>	<p>This is the key purpose for CDW and the motivation for practitioners – to make some changes to the world which will make it a better place to live.</p>
	<p>People may want to work with others who have shared experiences, so that they can make a bigger impact and create a team of people who can support each other.</p>	<p>CDW is different from other occupations in that it emphasises collective action as a way of tackling problems, that by coming together people have more power and influence to make a difference.</p>

	<p>People who have used the mental health system often want to create lasting change, so that others coming after them do not have to experience the same difficulties that they had.</p>	<p>Another key principle in CDW is about the sustainability if both community groups and communities themselves; both of these are echoed in current government policy.</p>
	<p>Volunteering is important and should be valued. But there comes a time for many people when they feel they should be respected by being paid, as others are who work alongside them.</p>	<p>Community members often sit as the unpaid experts on partnership boards, area panels and the like; they are expected to give their expertise for free to paid professionals and are not valued enough for this vital role.</p>
	<p>Many people with mental health problems say that paid work can help them manage their difficulties, and having a job can be both evidence and support for their continuing recovery. However, people have to decide for themselves when the right time comes and not be pushed into employment.</p>	<p>Activists may feel that they would like to move into paid employment as CDW as they have developed the skills and interest in this area of work; they may have gained expertise which they can use in other occupations. Community Development Learning programmes are often a spark to encourage people into further learning and employment</p>

Slide 2		
	<p>There are activists in all walks of life. Some people move on to paid work and others choose or have to remain as unpaid.</p> <p>Some can feel under pressure to get a job.</p>	<p>Honorarium</p> <p>This is where people's contribution is recognised by various ways of providing honorarium; care needs to be taken so it doesn't affect people's benefits and different interpretations of the rules are made in different areas of the country</p>
	<p>Some people will move on to get sessional or once off payments, to top up their incapacity benefits or part time wages. Getting it right to avoid penalties from the benefits system can be very difficult, and some move on to a job.</p>	<p>Short term contracts.</p> <p>There may be opportunities for short term pieces of work – for example around feasibility studies, community profiles, community research, community consultation – where people can follow through on their training in these areas and undertake paid pieces of research for community groups or statutory bodies.</p>
	<p>Some may choose to get a job in the mental health or community development field to create the changes they want to see, or take up another job where they can use transferable skills.</p>	<p>Creating or joining a social enterprise.</p> <p>People work with others within a social enterprise as a way of bringing about the changes they want to see – for example to offer improved care services, to tackle local environmental problems.</p>

Slide 3		
 <p>Support for individuals</p>	<p>Many of us from any background, but particularly those from a mental health background, find it hard to join community activities, and the Community Development Practitioner (CDP) can provide that vital one to one support to help us join the group activities we are interested in.</p> <p>The CDP can also link us to advice about how to protect our benefits when getting involved in activities.</p>	<p>Maintaining motivation</p> <p>All individuals and groups will go through difficult times when they are in the process of moving into different forms of activism and employment.</p> <p>CDW can act as a reminder of the better times, and of achievements so far, and help with working through the current problems to achieve their agreed longer-term aims and vision.</p>
 <p>Skill development</p>	<p>A CDP will have many skills they can share with their groups. Sometimes specialist skills will be needed, particularly for people setting up an enterprise and the CDP can link the groups to advisors, but this can be difficult. Local authority and other business advisors may feel that they have nothing to do with community groups and mental health service user groups.</p>	<p>Planning for sustainability.</p> <p>CDWs can help the group with development planning, business planning, and thinking through who wants their services, and how they can work together. CDW are good at group working and helping groups to work well together.</p>

	<p>All of us need a network of contacts when taking on a new role – different people who will help us out when times get hard or when we need advice and support. The CDP can help us develop this network, although again, drawing in business support can be hard in some areas.</p>	<p>Maintaining community links</p> <p>It is very easy for groups to get stuck into the business and forget about their community roots. CDW can support the group to maintain and refresh its community links and ensure its accountability to the community.</p>
<p>Slide 4</p>		
	<p>People with experience of mental health problems may remain looking in at the world they know best and where they have valued expertise. This can limit their business base and opportunities for getting involved in the wider community.</p>	<p>Employer focus.</p> <p>Some employers of CDW set very precise targets for their staff – which may limit the CDW's ability to respond to the needs and interests of the community, or to use the motivations within the community to bring about change. If the CDW is expected to only work with certain groups then they may exclude working with individuals and groups of people with a mental health focus.</p>
	<p>Part of the reason people may be reluctant to move out of mental health field is the discrimination and stigma around mental ill-health.</p>	<p>Feeling unskilled.</p> <p>Some CDW practitioners and local groups. may feel that it is too difficult to work with people with mental health problems. There is a fear and stigma.</p>

	<p>Funding from health sources may require that all participants in a project or enterprise use mental health or other health services, limiting the chance to involve other people.</p>	<p>Funding for community groups.</p> <p>The funding available may be specific to certain types of communities or groups of people and these may exclude any responsibility / opportunity for addressing the needs of mental health groups</p>
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Some practical examples of social enterprise responses to mental health and community needs:

Some practical examples of social enterprise responses to mental health and community needs:

Levenhulme Inspire - www.levenshulmelife.com/content/the-inspire-project : This project is not yet complete, but it will have a café, housing, radio station and other facilities which will become the hub of the local community. 40% of the people who will benefit from it will be older people, younger people, refugees or people with mental health problems, but people's backgrounds will not be identifiable.

Oasis: This is a café in a corner of a hospital, which is by nature an oasis to staff, patients, relatives and local people, offering a high quality, welcoming space where all are on a level and their circumstances unidentifiable. There are toys for children, wi-fi for workers, books to read, and a range of products on sale from local entrepreneurs (all with an experience of mental ill-health) including specialist bread, cakes, jewellery, artwork and more. Most staff and all volunteers running the café have experience of mental health problems. Oasis is a partnership between Bubble Enterprises (www.partnershipwtp.co.uk) and Pennine Care NHS Foundation Trust.

Cadenceworks - www.cadenceworks.co.uk: This enterprise trains and supports people from different backgrounds to develop their own business. They find that people with mental health problems benefit from the kind of business support given to many other groups disadvantaged in the job market.

Community Organisations for Mental Health; The Refugee Experience: Saeed Abdi

Saeed Abdi, the Co-ordinator of Maan Somali Mental Health in Sheffield introduced the work of the organisation, highlighted issues of mental distress within refugee communities and the importance of community based responses to these issues.

About Maan

Maan started as a self help group in 1992 and was constituted as a charity in 1994. It initially received funding from the National Lottery to deliver services and since then has secured monies from the local Primary Care Trust and a range of other bodies. Maan currently employs four full-time and two part-time staff and runs both a Mental Health Support Service and Floating Support Scheme. These services aim to:

- Act as a first point of contact for refugees, communities and Mental Health Trusts
- Reduce fear, stigma and taboo around mental illness in the community
- Help users/carers understand and demystify illness, medications and the treatment process
- Identify needs and raise awareness in the community of available services
- Help service users through the referral process, medication, CPA, hospitalisation and discharge
- Work with service providers to develop culturally appropriate services and more effectively understand community needs
- Support carers and provide basic counselling services for women – as well as advocacy, outreach support, interpretation and escort people to appointments/monitoring medication etc
- Address general social needs – in terms of education/training, benefits advice, housing support and social events.

What is, however, critical, is that Maan takes a holistic approach. It is not just about mental illness – but looking at the whole person, the diversity of their needs and the community context in which they live.

“Maan is a bridge for the community into services. And it is then a bridge for service providers into the community. A two way bridge...as providers do not have a way into the community or a knowledge that enables them to offer culturally sensitive services and the community may not understand services that are available.”

Mental Health and Refugee Communities

The Somali community struggles to overcome various barriers due to language, culture, poverty and social exclusion. This adversely affects community health, education and socio-economic standards which translates into:

- Higher than average mental health problems
- Higher than average unemployment and poverty
- High under-achievement in schools
- Higher than average family break down
- Epidemic Khat abuse especially among men,

But let us put that into context. In May 2008, BBC Look North (the local news service) undertook a survey of about 2,000 people and asked them about how they had been affected by the floods in Yorkshire the previous year. Of those who replied:

- 84% said their health had been affected in some way
- 44% said their mental health had been affected in some way
- 26% said their mental health had been significantly affected
- 42% said the floods had affected their physical health – with 32% reporting there had been a significant affect
- 32% said that there had been a negative impact on family relationships
- Others reported that their children remained afraid of heavy rain.

Now the floods were a serious misfortune for people. They have been out off their homes – some for almost a year. But imagine the same affects for refugees who have lost their homes and may never be able to return. Think of the impact on their mental health. Think of post traumatic stress and all the things that people – children – have seen in their lives that made them refugees.

Somalis believe mental health problems can be caused by:

- Possession i.e. by demons / jinn
- Witchcraft / magic
- Hereditary issues
- Curses, evil eye, hubris
- Blood / murder / evil crime
- Insurmountable problems / worry

Community responses to mental distress vary from:

- Exorcism / Holy intervention to drive bad spirits out
- Alternative medicine
- Physical health support

- Social and family support
- Financial support
- Marriage?
- Conventional doctors
- Lock up

Developing a community based response to mental illness

As we can see, mental health – mental illness - is difficult to address ‘head on’ within Somali – and other – refugee communities. Our starting point therefore is really as a refugee community organisation – rather than a mental health agency – although the words appear in our title. So we work with the community’s issues to:

- Highlight the vital importance of housing in mental well being: in the absence of a comprehensive strategy for addressing the needs of refugees, most Somali’s have ended up in poor housing, often on estates with high levels of crime, drug use – and hostile attitudes to refugees and new arrivals. All these social factors have an impact on mental well being.
- Tackling the poverty and high rates of unemployment within the community
- Ensuring that statutory agencies understand community needs and are better able to respond to not only mental health in isolation – but address the whole needs of the individual – social and economic as well as health.
- Raising awareness of the long term impacts of peoples’ previous experiences – of refugee camps, of fleeing for safety, the things they have seen in war and the very long term effects this can have.

Much of this involves offering very practical services that people understand – sorting out benefits, helping people access housing and sustain their tenancies and advocacy. This goes hand in hand with challenging some of the stereotypes about Somalis and refugees within host communities But it is that practical work – basic community services – that even begins to allow us to address mental health in communities where the very term involves a high degree of stigma and isolation.

But finally, one of the major issues for Maan – and the community – is funding. We are not saying that you have to fund us forever – but when there are long term needs – then a long term response is needed. Yet, just as there is begging fatigue for refugee community organisations – so there is donor fatigue. We recently applied to a charitable trust for support and they said – *‘you receive money from the Primary Care Trust, so they should fund you’*. We talked to the PCT and they said *‘we do not fund 100%.’* So it is hard – and for small community organisations – it is getting more difficult.

We need to show that we are effective. We need to show that we are responding to real community needs. But what is required in turn is a much longer commitment of funds to groups working at a community level to address the needs of refugee communities – and enable them to do this in a way that tackles poverty, exclusion and poor housing – things that affect the mental health of all – not just refugees.

For more discussion by participants on the issue of access to resources – [click here](#).

7. Conclusions

Common Grounds? Key Learning and Action Points

Following presentation, the final workshops of the day and plenary session focused on:

- questions arising from the discussions in what had been planned as an exploratory event
- current gaps in the community development and service user agenda
- practical suggestions for taking forward the 'common grounds' agenda and building positive mental health alliances between service user groups and community development.

The **key questions** identified were:

The event had demonstrated that there were benefits from dialogue between service user groups and those involved in community development. In the words of one participant – *“This has broadened my horizons. I can see that what I am trying to achieve in changing (mental health) services, others are trying to do in their community. We can learn a lot from each other.”* How can such network development be resources at a regional and national level?

“Service users and community (activists) are often talking about the same things – self determination, empowerment, social justice, change....But too often the jargon gets in the way – or we are using different words to express the same idea. How can we address this?”

“There can be a lot of tension between the agencies/providers, staff and service users/community activists. Yet we are all saying we are working for the same things. Better services, better lives. How do we break down those antagonisms? How do we get to a place where we are genuinely working together to achieve what we all say we want.”

Community development workers and service user groups need to be more astute in using the media to challenge stereotypes and stigma – of certain communities and mental health issues. How do we do this? How do we get across positive messages in a media dominated by 'bad news' on mental health and certain communities?

“How do we get the ear of commissioners to support joint community development/service user work and network development.”

The **key gaps** identified were:

In both community development and mental health, there is a gap between work with adults and services/work with children and young people. More needs to be done to address:

- The impact of adult mental health issues on children and young people
- School involvement in promoting understandings of mental health and tackling stigma
- Young people as part of the community. Too often they are seen as a problem and separate from ideas of community. Youth Work training has become 'divorced' from the wider community context and this needs addressing in professional qualifying programmes.

The **suggestions for ways forward** included:

Ensuring that professional workers in community development and service user participation take activists/service users with them to networking/conference events. Networking should not just be for the paid professional. Those organising conferences and network events need to be convinced of the value of involving activists and service users.

Lobbying Universities, Colleges and other training providers to ensure that ideas of community and community development are included in pre-qualifying and continuing professional development programmes in the field of mental health. An understanding of mental health issues, related to social exclusion, should be included in any revisions of the community development occupational standards.

Local, regional and national organisations active in the fields of community development and service user engagement should be encouraged to offer more networking opportunities which address the themes of communities and mental health. We should lobby national agencies such as MIND, Rethink, Community Development Exchange etc. to think more about the relationship between mental health and thriving communities.

Links need to be created between community development and mental health specific websites. At present they are too 'topic specific' and do not enable people to make the links between mental health and community development.

Concluding Remarks

'Common Grounds' aimed to explore whether there was shared learning between mental health service user groups and community development work. Participant discussion, and subsequent feedback, indicates that there is and that there is a need for further networking activity.

The Centre of Excellence in Interdisciplinary Mental Health (University of Birmingham) and the Federation for Community Development Learning are committed to driving forward this shared agenda with partners organisations and will be seeking the resources to enable this to happen at a national level. In the meantime we would encourage local and regional groupings to act on the recommendations of participants in 'Common Grounds':

"The message from today us that we are not alone. There are shared struggles. Service users and community activists can make a difference. We can improve services. We can change things for the better. But we need to work together. Mental

health is about the whole person, the whole community – so we cannot do this on our own. Together we can be stronger.”



APPENDIX 1

Common Grounds?

Building Alliances for Positive Mental Health: Communities, Community Development and Service User Groups

21st July 2008

About the Presenters

Saeed Abdi is the Co-ordinator and team leader at Maan Somali Mental Health in Sheffield, and Chair of Maan Somali Healthy Mind Liverpool.

Ann Davis is Professor of Social Work and Director of the Centre of Excellence in Interdisciplinary Mental Health (CEIMH), The University of Birmingham. Ann has been involved in mental health social work practice, research and education for over thirty years.

Dr Val Harris has been involved in community development work for many years; she is a practitioner and a writer - editing the Community Work Skills Manual and writing many different resource packs to support community development learning.

Angela Hill is a Board member with Users in Partnership. She is a service user and carer as well as being a Director of the charity 'Family Care Trust'.

Tony Kirk is the Development Worker with Users in Partnership. He has been involved in mental health service movements since 1997 including working as User Involvement Officer in Sandwell.

Janice Marks is Head of Agency at the Federation for Community Development Learning, and is a founder trustee of Maan in Sheffield

Angus McCabe is a Senior Research Fellow in the Institute of Applied Social Studies and is based at CEIMH, University of Birmingham. His background is in community development and he has worked with a range of service user groups.

Patience Seebohm is a self employed researcher. Most of her work now involves participatory action research on mental health, community development, race equality and employment issues.

Sonia Thompson is currently a self-employed consultant and former University Lecturer in Community and Youth Work. She has been actively involved in community development for over twenty years particularly with the BME community and has contributed to the training framework for Community Development workers in BME communities led by the Department of Health and the National Institute for Mental Health England.

APPENDIX 2

Common Grounds?

Building Alliances for Positive Mental Health

21 July 2008

Attendance List

Name	Sector/Location
Saeed Abdi	Maan Somali Mental Health, Sheffield
Sundee Bassi	Main Street Resource Centre, Birmingham
Bob Blatchford	Senior Practitioner (Social Work) CMHT, Nottingham
Krishna Bhatti	Community Development Worker, Nottinghamshire Healthcare NHS Trust
Mike Bush	Mental Health Services Survivor, Leeds
Gill Crawshaw	Liaison & Development Worker, Volition, Leeds
Barbara Crosland	Social Inclusion Lead, CSIP West Midlands
Ann Davis	Professor of Social work and Director of CEIMH, University of Birmingham
Shirley Dean	Chairperson – Stuff, Stockport
Myola Edwards	Community Development Worker, Barnardo's, Birmingham
Sergio Gonzalez	Hereford PCT
Karen Hirons	Patient and Public Involvement Manager, South Staffs & Shropshire NHS Trust
Rachel Hannah	PR Officer, Worcester Mental Health Network

Nazrul Haque	CDW Worcester Mental Health Partnership NHS Trust
Belinda Harries	Service User, London
Val Harris	Independent Trainer and Consultant
David Henry	Diversity Advisor, Rampton Hospital
Angela Hill	Users in Partnership, Birmingham
Jayesh Jani	Community Development Worker, Nottinghamshire Healthcare NHS Trust
Tony Kirk	Users in Partnership, Birmingham
Ambrose Koryang	Community Development Worker, Midland Heart, Birmingham
Janice Marks	Head of Agency, Federation for Community Development Learning
Angus McCabe	Senior Research Fellow, Institute of Applied Social Studies and CEIMH, University of Birmingham
Ruth Morris	South East Regional Co-ordinator, Mental Health Mentoring and Befriending, Eccles
Sue Morris	Educational Psychology Programme Director, University of Birmingham
Jenifer Murain	CPN, Washwood Heath CMHT
Samina Naz	Community Development Worker, Nottinghamshire Healthcare NHS Trust
Mary Nettle	Mental Health User Consultant, Cirencester
Michael O'Sullivan	Senior Staff Development Officer, Derbyshire Mental Health Trust
Rachel Porter	Development Officer, Worcestershire Mental Health Network

Annette Rimmer	Lecturer, University of Salford
Jackie Sanderson	Service User, Stockport
Vijay Saul	CPN, Washwood Heath, Birmingham and Solihull CMHT
Alice Sawyerr	Lecturer (Psychology, Mental Health and Systemic Therapy) Royal Holloway University of London
Patience Seebohm	Researcher on Mental Health Participation, Community Development, Race Equality and Employment Issues
Lesley Talbot-Strettle	NICE West Midlands
Rhanish Thier	Community Development Worker, South Staffs & Shropshire NHS Trust
Cynthia Thomas	Maan Somali Mental Health, Sheffield
Sonia Thompson	Self Employed Consultant and former Lecturer
Colin Tysall	Service User, Coventry
Val Woodward	Take Part in Governance



The Centre of Excellence in Interdisciplinary Mental Health (CEIMH) is one of 74 Centres selected for funding by the Higher Education Funding Council for England (HEFCE) to promote excellence in teaching and learning in higher education. Building on the University of Birmingham's established record in mental health education, CEIMH has developed a dynamic and collaborative partnership between six disciplines in the University as well as other key local, national and international mental health agencies and service user and carer organisations.

For further information on CEIMH visit www.ceimh.bham.ac.uk



The Federation for Community Development Learning supports a network of individuals, organisations and groups interested in community development learning and training to share information and good training practice, to learn from each other and to provide good opportunities for community development learning.

FCDL works at a national level to develop new arrangements for community work training and qualifications that are accessible and relevant to those involved in community work activities.

For further information on FCDL visit www.fcdl.org.uk