

Care Services Improvement Partnership 

National Institute for
Mental Health in England



Valuing Involvement

**Strengthening Service User and
Carer Involvement in NIMHE**

**Ways of working with diverse
groups and communities**

**A product of the Making a Real Difference Project (see overview
for details)**

Overview

The Making a Real Difference Project was undertaken in direct response to the HASCAS review of service user and carer involvement in NIMHE. This resulted in the Making a Real Difference report.

The following guidelines are designed to address some of the recommendations made within the report. They provide practical ways of working with diverse groups and communities.

This document will support NIMHE, and its staff, address how they can broaden the diversity of people involved and benefit fully from the expertise held within more marginalised groups and communities.

Who are the Guidelines for?

New NIMHE Staff and Volunteers

- All new staff should familiarise themselves with the Ways of Working With Diverse Groups and Communities document to ensure that they gain the full benefit of the guidelines when planning and delivering their work programmes. Any queries should be discussed with their line manager.
- All new work programmes should supported by these guidelines.

Existing NIMHE Staff and Volunteers

- Existing staff members should familiarise themselves with the guidelines.
- Existing staff should ensure that their work is supported by the guidelines when broadening the diversity of people, groups and communities involved in their work programmes.
- Any new work programmes should be supported by the guidelines.

People Sharing Their Expertise to Inform NIMHE's Work

- All people should be made aware of the expectations within the guidelines so that they are clear about what to expect when they are involved with NIMHE and its work programmes.

NIMHE Boards, Commissioners and Performance Managers (including external stakeholders)

- All NIMHE focus, reference and performance management groups should be set up using this document to support the engagement of people from diverse and marginalised groups and communities.

Acknowledgements

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The work was informed and overseen by the members of the West Midlands Making a Real Difference **Work Group 4 Steering Group**, comprising staff, service users and carer representation. Members were:

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- Action 16 National Parental Mental Health Network
- Carers in Partnership (West Midlands)
- Users in Partnership (West Midlands)
- West Midlands Personality Disorder Network
- West Midlands Users in Partnership Older Person's Group (including carer participants)
- West Midlands Users in Partnership Women's Leads (including carer participants)

Specific **Consultation** sessions were held with the following groups

- Black and Minority Ethnic Communities: Birmingham, 12th October 2006. Conference facilitated by the Catchafiya network- special thanks to Dominic Walker, Julie-Jaye Charles and all co- facilitators
- Primary Care: Birmingham, 29th November 2006. Focus group facilitated by Pen Mendonca
- Forensic services. Focus Group and interviews with residents of Ardneigh Medium Secure unit- facilitated by Becky Derham from User Voice, Birmingham
- Prisons. November 8th and 10th 2006- Two focus groups with residents of HMP Hewell Grange, Worcestershire. Facilitated by Debbie Evans and colleagues from University College Worcester.

- Lesbian/ Gay/ Bisexual/ Transgender communities. Focus group and interviews with BI-GLAD (Birmingham Gays and Lesbians Against Depression)- facilitated by Noveed Zubair

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Dr JoyAnn Andrews (University of Staffordshire, Centre of Ageing and Mental Health)

Dr Jan Wallcraft (Independent user consultant/ previously Sainsbury Centre for Mental Health and NIMHE Experts by Experience Fellow)

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All members of the National Making a Real Difference Steering Group

All Making A Real Difference Work Group Leads

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Introduction

The “*Making A Real Difference*” Report (HASCAS 2005) recommends that NIMHE ensures it has a broad range of ways of engaging with a broad range of people experiencing mental distress and their families and carers. This includes going to where people meet, informal events and focused approaches to ascertaining service user and carer views. By offering more flexible and creative ways of getting involved, NIMHE can engage with a wider range of groups and communities who are currently marginalised within the organisation.

This document gives some general principles when deciding on ways of engaging with service users and carers then suggests some of the different approaches that can be used. It is not intended as a comprehensive or detailed guide.

For more practical examples of working with service users and carers from diverse group, see the forthcoming report from the Pollen Shop/ Valuing People Support Team “*Talking to people and building effective partnerships - Engaging people who are traditionally excluded from consultation processes*” (CSIP 2006).

Chapter 1 - General Principles

- ✓ Regional Development Centres and National Programmes need to develop a wider range of ways of engaging with diverse groups
- ✓ This includes a mix of formal and informal techniques, face-face and indirect methods; individual and group work
- ✓ There should be less reliance on written consultation, large conferences and formal meetings, which tend to be professionally dominated or are more accessible to people with more experience of involvement, work and education
- ✓ Groups that have been particularly excluded by formal approaches include black and minority ethnic communities, children and young people, people with high support needs and people with learning disabilities
- ✓ Everyone has the right to take part People have different ways of contributing, and different types of knowledge, which should all be valued
- ✓ It is important to think of the needs of all communities, even if they are numerically small- consider joining up with another region which may have more experience, or working in partnership with another organisation

Chapter 2 – Choosing Methods

Choice of methods will be influenced by whether the engagement is:

Consultation	<ul style="list-style-type: none"> • One off or time limited process • Getting views on a specific issue or plan • No direct say for communities over how it is done or what will happen as a result
Participation	<ul style="list-style-type: none"> • Involving people from the start of a project or committee to the end • Partnership with communities including decision making processes
Involvement	<ul style="list-style-type: none"> • Working with people over a longer time • Community input aiming to change how an organisation works and influence policy

When planning work with service users and carers from diverse groups and communities, be clear on purpose and resources available (including time and skills as well as money). Check if there are existing networks or sources of information that you can use. Then consider:

Audience	<ul style="list-style-type: none"> • Who do you want to involve and why?
Methods	<ul style="list-style-type: none"> • What methods and approaches are realistically available? • Who are the people most likely to respond to these?
Equalities Issues	<ul style="list-style-type: none"> • Are there any people for whom the method may not be appropriate? • What additional methods could be appropriate to get the views of people who are excluded by this method?
Evaluation	<ul style="list-style-type: none"> • How will you know if it has included people? • How will you share learning?

Chapter 3 – Different ways of reaching people

3.1 Community Outreach

- Get information about involvement around community venues, for example, libraries, youth clubs, GP surgeries, leisure centres, gay bars and religious venues. Use contacts with local knowledge to make distribution easier, for instance, advocacy groups, Primary Care Graduate Workers, Community Development Workers or Patient Advice and Liaison Services (PALS)
- Work through a trusted third party, for example, commission a local voluntary group to undertake consultative work with a particular community, use volunteers who know the culture or areas or employ session workers.
- Raise NIMHE's profile at existing community events, for example, have a stall or float at cultural events such as Refugee Week, Pride or the International Day of Disabled People; or a drop in session at a local venue
- Use the press to highlight opportunities to get involved. Local papers are often keen for an interesting "angle" and many give free coverage; as well as specialist press, for example, for the Gay and Lesbian communities
- Local radio can also access a different audience, for example, young people or black and minority ethnic (BME) communities, including people who stay at home

3.2 Community Research

- **Participatory or Peer Research**
People from a particular background designing and delivering research can be powerful in getting other people to engage
- **Surveys and Questionnaires**
Can be online, postal or by phone to gauge the views of people who do not go to meetings
- **Interviews with Individuals**
Helpful for sensitive issues
- **Focus Groups** (either one off or repeated)
If facilitated well allow everyone to take part and share ideas

- **Rapid Appraisal**
Generates a lot of qualitative information about an area or issues in a quick and succinct manner
- **Snowballing**
Having direct contact with people who are already engaged who then use their informal networks to identify who else may take part is a good way of recruiting people to take part in something where there are issues of stigma, for example, around HIV or where there are no established networks, for example, for BME communities in rural areas

3.3 Making Things Less Formal

- Provide opportunities to relax while they share ideas- for example, mix with service users and carers over a working lunch
- Give time and space for service users and carers from diverse background to lean together, for example, hold an “away day” for active members of networks
- Have fun, social events such as arts or sport can attract people’s interest for the first time, which can be built on.
- Allow time for small group working at bigger events. Consider using things like role plays and ice breaking exercises to liven up formal proceedings (although some people do not like taking part in games)
- Consider creative ways for people to explore complex issues, for example, use of drama workshops followed by a discussion or making a video
- Offer interactive ways of responding, for example, video booths, making a banner, drawing or graffiti walls, graphic recording

3.4 Using technology

- Some service users and carers may prefer to get involved through email discussion forums, for example, if they find going to meetings stressful or wish to persevere their anonymity. The new CSIP Knowledge Community should be “user friendly” to support this. There are also existing “virtual” networks such as Borderline UK.
- Using the web can also reach people who are not connected to any service user or carer groups, or who are not using services.

- However, a lot of people do not have access to the internet, so this should never be the only way of getting information or sharing views. Where possible, active service users and carers should be supported to access technology through IT training or provision of equipment
- Web design also needs to meet accessibility standards
- Telephone conferencing is relatively cheap and simple if travel to a meeting is difficult, although people may need time to get used to how it works

3.5 Different Types of Meetings

Good communication skills such as active listening and empathy are more important than using particular techniques with groups and communities. However, some ideas for varying the format of events are listed below.

- **Open Space Events**
Participants themselves prioritise issues and organise workshops around a core theme, then turn detailed discussions into action plans
- **Citizens Juries**
This is a way of getting people together to make a recommendation on a difficult issue faced by an organisation. The jury hears evidence from different perspectives and ask questions.
- **Independent Advisory Group**
A group of people recruited on the basis of their experience, for example, of having a disability, whom meet regularly to provide expert advice for an organisation on disability issues. With the upcoming Equalities Act, other statutory organisations will need to consult with diverse groups, and there may be opportunities for NIMHE or CSIP to help develop Independent Advisory Groups

For more detail on community development methods, including resource implications, see:

Scottish Executive Central Research Unit and Equality Unit"- "Good Practice Guidance- Consultation with Equalities Groups", 2002, Reid/ Howie Associates
<http://www.scotland.gov.uk/Publications/2002/06/14850/5332>

Scottish Centre for Regeneration- Communities Scotland, "Community Engagement How to Guide: Support for Ethnic Minorities"
www.scr.communitiesscotland.gov.uk

Glossary

The Glossary of terms used within the Making a Real Difference Report is;

Carer	Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.
Care Services Improvement Partnership (CSIP)	An organization formed in April 2005 to bring together NIMHE with other Department of Health groups which cover people with learning disabilities, older people and children and young people.
Experts by Experience (EbE)	A national service user and carer group which was part of NIMHE.
Local Implementation Team (LIT)	An organisation made up of stakeholders from different organisations including service users, carers, health and social services staff. Responsible for agreeing the direction for mental health services locally and for implementing national mental health policy.
National Institute for Mental Health England (NIMHE)	Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.
PCT (Primary Care Trust)	Organisations which are based in primary care and responsible for commissioning health services for the local population.
Programme Lead	A member of NIMHE staff responsible for leading a programme of NIMHE's work either at a national or a regional level.
Regional Development Centre (RDC)	NIMHE has eight regional development centres.
Service user	Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems

Other Terms used within this report include;

HASCAS – Health and Social Care Advisory Service	An advisory service working in all aspects of mental health and older peoples services – HASCAS wrote the Making a Real Difference Report
Directors	The senior managers in each CSIP Development Centre
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.
PRINCE2	PRojects IN Controlled Environments, a structured way of managing projects.
Work Group	One of the seven groups that were tasked with developing the Making a Real Difference products.
Project Governance	A term to describe how the whole project was monitored and managed.
Terms of Reference	A description or the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.

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