

Care Services Improvement Partnership **CSIP**

National Institute for
Mental Health in England



Valuing Involvement

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

**Guidelines for making events
more inclusive**

**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 elements highlighted within the report. They will set out some suggestions for effective event planning for NIMHE and its staff to use when organising any event or meeting that people from diverse groups who are involved with NIMHE will be attending.

The guidelines for making events more inclusive support the minimum standards for engaging diverse groups in NIMHE's work programmes.

Who are the Guidelines for?

New NIMHE Staff and Volunteers

- All new staff should familiarise themselves with the guidelines to ensure that they have a full understanding of the expectations NIMHE has for them. Any queries should be discussed with their line manager.
- All new work programmes should be developed using the guidelines.

Existing NIMHE Staff and Volunteers

- Existing staff members should familiarise themselves with the guidelines.
- Existing staff should ensure that their work programmes make best use of the guidelines to support the involvement of people from diverse and often marginalised groups or communities.
- Any new work programmes should ensure that the guidelines are used when planning any event.

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 events should be organised and run in line with guidelines.
- All monitoring and evaluation of events should include measures of effective communication.

Acknowledgements

The Minimum Standards and supporting documents were developed and written by Barbara Crosland on behalf of the Making a Real Difference Project.

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:

David Conlon

Angela Hill

Alastair McIntyre

Amanda Rose

Peter Woodhams

Simon Foster

Tony Kirk

Jackie Rankin

Ranjit Senghera

The process was informed by the expertise of the participants within the following **groups and networks**:

- 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 Ardneleigh 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

Many **individuals** gave their time and expertise, including:

Rachel Heywood (Valuing People)
 Sue Imlack (Solihull User Involvement worker)
 Tricia Nicoll (Having A Voice)
 Jeannette Partridge
 Loris Tapper
 Colin Gell

The **Literature Review** of Diversity in Mental Health Service User and Carer Involvement has been undertaken with the support of a range of groups and organisations, who will be formally credited when the report is published. However, particular thanks go to the main authors:

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)

The **personal support** of the following people to the process is also gratefully recorded:

Liam Gilfellow (Making A Real Difference Project Manager)

All members of the National Making a Real Difference Steering Group

All Making A Real Difference Work Group Leads

Ian McPherson and Sandra Hudson (CSIP West Midlands)

We would also like to say thank you to everyone who did not necessarily belong to any of the above groups but who also contributed to this document!

Contents

Introduction	6
Chapter 1 – Planning an Event	7
1.1 Timing and Venue.....	7
1.2 Format of Events	8
1.3 Meeting Access Requirements	9
Chapter 2 – Supporting People at Events	10
2.1 General Support	10
2.2 Black and Minority Ethnic Communities	10
2.3 People with Disabilities	11
2.4 People with Learning Disabilities	11
2.5 People with Visual Impairments	12
2.6 People with Hearing Impairments	12
2.7 People with Dementia	13
2.8 Children and Young People	13
Bibliography and References.....	14
Glossary of Terms used	14

Introduction

The Making a Real Difference report (which was commissioned to review service user and carer involvement within NIMHE) recommended that NIMHE use a broad approach to involving people with experience of mental health problems and their friends and families who care for them, with both formal and informal ways of getting feedback. By paying attention to the timing, venue, information and support available NIMHE can make its events more enjoyable and effective for a wider range of groups and communities.

The Guidelines should be used alongside:

- the Minimum Standards for Engaging Diverse Groups and Communities (Making a Real Difference Resource Pack)
- Guidelines for;
 - Supporting Communication With Diverse Groups and Communities
 - Ways of Working With Diverse Groups and Communities (Making a Real Difference Resource Pack)
- Recommendations for Organising Resources to Support Wider Involvement (Making a Real Difference Resource Pack)
- The guidelines should also be read and used in conjunction with all of the other documents within the 'Making a Real Difference Involvement Resource Pack.'

The guidelines refer to “events” or “meetings” for short. This includes any occasion where people are invited to take part by NIMHE, for example, large and small meetings, conferences, interview panels, training, focus groups, and open days. They are intended as a starting point only. When working with a particular group or community ask for the advice of people from that background when designing an event or other activity.

Chapter 1 – Planning an Event

When planning the involvement of people with experience of mental illness and their friends and family who care for them, it is worth considering whether bringing people together physically is the best way of achieving what is wanted.

Alternative means of engagement, for example, teleconferences, e-mail forums or postal consultation may be equally or more appropriate for some purposes. More detail can be found in the **Guidelines for Supporting Communication with Diverse Groups** (Making a Real Difference Resource Pack).

Accessibility should be built into the whole process of planning an event or meeting from the beginning to the final evaluation. This should be implemented and reviewed through the standard Regional Development Centre or national event organisation processes and protocols.

1.1 Timing and Venue

- ✓ When setting a date, remember that many parents find making meetings difficult during school holidays
- ✓ Many service users and carers do not like events to start too early or finish too late, especially in winter or if people are travelling long distances. Some concessionary transport schemes also have time restrictions to consider. Times between 10.30 and 3.30 are suggested as appropriate
- ✓ However, people who are working or studying full time may only be able to attend evening events or quick “drop-in” sessions local to them, for example, over a lunchtime. This may have particular relevance if the target audience includes the general public or primary care users, as well as many carers.
- ✓ Check access by public transport and parking, including disabled parking. Send clear maps and directions to delegates
- ✓ If facilities are appropriate, use community or voluntary sector venues instead of conference centres and hotels. People may feel more comfortable here, and it supports grass roots organisations. However, some people may feel uncomfortable in religious venues
- ✓ RDC travel agents should be able to advise on accessibility if booking overnight accommodation for a speaker or delegate with a disability. If not, the English Tourist Board should be able to help- <http://www.enjoyengland.com/book/accommodation/>
- ✓ It is also useful to keep a list of hotels in the region with accessible facilities

1.2 Format of Events

- ✓ Plan regular breaks- at least every hour if possible. Make it clear that people are free to take a comfort break at any time
- ✓ Make sure that breaks are long enough for everyone to eat and drink, take medication and go to the toilet
- ✓ Make sure that there is enough time in the programme for people with particular information needs to keep up. For example, a meeting where someone is assisted by a Deaf-Blind guide may need at least 50% more time
- ✓ Go through the “house keeping” rules at the start of the event; with particular attention to facilities and evacuation procedures for Disabled people (if appropriate)
- ✓ Make sure support workers and interpreters are included in numbers for catering, and are briefed on what is happening during the event and that they get the programme in advance. If possible, use the same workers regularly.
- ✓ Keep presentation short (15-20 minutes is ideal) and use a range of styles to help people keep concentration
- ✓ Having a quiet room or complementary therapies may help people relax

1.3 Meeting Access Requirements

- ✓ If an access issue arises for a group or individual which has not been dealt with in the original plans every reasonable effort should be made to address it.
- ✓ It is not possible to predict or prevent all access issues beforehand - common sense and flexibility are essential when responding to problems
- ✓ If a request cannot be accommodated a proper explanation should be given.
- ✓ Ask attendees in advance if they have any access, dietary or other requirements. For an example of a standardised form to go out with booking information see the SCIE (Social Care Institute for Excellence) Accessibility Guidelines "*How to make events accessible*", Appendix A (June 2005)
<http://www.scie.org.uk/publications/misc/accessguidelines-events.pdf>
- ✓ If a venue has not been used before one of the organisers should have a look around, even if it is described as having access for disabled people. This will confirm its suitability and help with planning for any access requirements. For an example of a venue accessibility checklist see the SCIE (Social Care Institute for Excellence) Accessibility Guidelines Appendix B (*Link as above*)
- ✓ Try to get papers sent out in advance in people's preferred formats (see **Guidelines on Communicating with Diverse Groups**). For conferences, make sure presentations get to the organisers in good time to enable this
- ✓ Be aware of gender issues. Some service users and carers, including people from Black and Minority Ethnic communities may be more comfortable talking part in things with people of the same gender. Other service users and carers may wish to have access to a member of staff from the same gender, particularly for emotional support if a sensitive issue such as violence or abuse is being discussed
- ✓ Make provision for child care, or caring responsibilities for adult relatives. This can be by offering to care expenses in line with the NIMHE policy. If an event is likely to attract parents think about crèche arrangements (which must meet appropriate quality standards), or letting people bring children. Parents may need to leave early to pick up children.

Chapter 2 – Supporting People at Events

2.1 General Support

- ✓ Be aware that people may have “invisible” support needs. For example, people with mental health problems such as anxiety may need personal support to feel confident enough to attend
- ✓ Don’t make assumptions about what support people need- ask!
- ✓ Use microphone systems in larger venues including roving microphone for the audience
- ✓ Be attentive without making people feel “different”, and always talk to the person, not their supporter (if they have on)
- ✓ Keeping to ground rules, the Chair inviting one person to speak at a time, makes it easier for everyone to take part

2.2 Black and Minority Ethnic Communities

- ✓ Be aware of major religious festival times and any implications these may have - for information on significant dates and other aspects of the main faiths, see www.interfaithcalendar.org. For example, during Ramadan, think about access to a space for prayers, and setting food aside so that Muslim people can eat it after nightfall.
- ✓ Some users and carers who do not have English as a first language may feel more comfortable having someone they know come with them to meetings as an informal interpreter. However, don’t assume this- professional interpreting and translating should be provided if requested or the need is anticipated. Regional Development Centres should have a list of community language services prepared.
- ✓ For major events infrared or radio systems can be used to provide translation services but check this does not interfere with any hearing aid systems in use
- ✓ Check that any dietary requirements are catered for, for example, Halal or Kosher meat. Use local caterers from the community if possible. Label foods clearly and ensure catering staff are aware of any dietary needs

2.3 People with Disabilities

- ✓ Some disabled people may need individual support during an event. This may be to help people with personal care or to help someone with a learning disability to make notes. Some people may bring an assistance dog
- ✓ Support needs should be discussed with an individual. It may be that with prior knowledge NIMHE staff can provide general assistance to a service user or carer.
- ✓ However, a disabled person may prefer to have their own personal assistant or supporter. NIMHE should be ready to pay support costs if necessary to enable a person to attend an event (in line with the **Valuing Involvement - Payment and Reimbursement Policy Guidance**)
- ✓ NIMHE Regional Development Centres should also be able to advise on arranging support from an agency or advocacy scheme on behalf of someone (a list of trained personal assistants may be available from local Centres for Independent or Inclusive Living- see <http://www.ncil.org.uk/>)
- ✓ Make sure the room layout makes it easy for people to see things and move around
- ✓ If using a video check if an audio described version is available for people with visual impairments or with subtitles in English or British Sign Language (BSL)

2.4 People with Learning Disabilities

- ✓ A few people may need a Makaton signer and information
- ✓ Props like “traffic light cards” can help people participate with more confidence, being able to hold up a red “stop” card when they don’t understand something
- ✓ Small group work may be easier to take part in than a big meeting, especially if people don’t know each other already
- ✓ For more information, go to www.easyinfo.org.uk or

2.5 People with Visual Impairments

- ✓ Make sure there is clear signage, and that there are no obvious physical barriers, for example, glass doors can be dangerous and should be clearly marked
- ✓ Introduce yourself when a person with a visual impairment arrives, and introduce them to other people
- ✓ Ask if they want any help guiding them. If guiding someone, describe where you are going to them, for example, when they get to the stairs
- ✓ For more information go to the Royal National Institute for the Blind www.mib.org.uk

2.6 People with Hearing Impairments

- ✓ Some people with hearing impairments may use an induction loop system, either built into a venue or portable (it may be worth NIMHE Regional Development Centres buying one)
- ✓ Others may use British Sign Language (BSL) interpreters, relay interpreters, palantypists (a speech to text recorder) or lip reading
- ✓ A list of BSL interpreters should be available from local deaf organisations (but services need to be booked well in advance). For complicated or lengthy meetings more than one interpreter is needed.
- ✓ Make sure the room layout and lighting facilitates lip reading or signing and that people speak clearly
- ✓ For more information go to the Royal National Institute for Deaf and Hard of Hearing People www.rnid.org.uk or the Council for the Advancement of Communication with Deaf People www.cacdp.org.uk

2.7 People with Dementia

- ✓ Allow people with dementia to talk about something whenever it comes to them rather than sticking rigidly to an agenda or else the thought may be lost
- ✓ Provide material as a stimulus if discussing abstract ideas
- ✓ Arrange for staff, an advocate or relative to support a person in a meeting if appropriate but be sure they are aware of their role and boundaries
- ✓ Choose a venue that is comfortable in an area which feels safe
- ✓ Minimise verbal and visual distractions and interruptions so people can concentrate on what is being discussed in the meeting
- ✓ For more information, see *Cantley et al "Listen to Us" (2005)*

2.8 Children and Young People

- ✓ For events aimed at children or young people events in evenings, academic holidays and weekends may be most appropriate
- ✓ Ensure that participation is a safe activity for children and young people with issues of informed consent (including parental consent or equivalent in the case of younger children), confidentiality and child protection identified and addressed
- ✓ Incorporate fun activities, this can help break the ice at the beginning of meetings and balance the hard work
- ✓ Create a relaxed atmosphere where children and young people feel comfortable, for example, having music, access to drinks and snacks, arranging chairs in an informal way
- ✓ Be aware of power dynamics. Children and young people may feel intimidated if the group is dominated by adults or professionals
- ✓ For more information see SCIE Practice Guide 6: "*Involving children and young people in developing social care*"
www.scie.org.uk/publications/practiceguides/practiceguide06
- ✓ Make sure that facilitators are confident in working with children and young people

Bibliography and References

Cantley C., Woodhouse J. and Smith M. *“Listen to us: Involving people with dementia in planning and developing services”*, Dementia North/ Northumbria University” (2005)

SCIE Accessibility Guidelines *“How to make events accessible”* June 2005, SCIE

SCIE Practice Guide 6: *“Involving children and young people in developing social care”* (2005)

Glossary

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

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.

RATIFYING BODY
DATE RATIFIED
NEXT REVIEW DATE
TO BE APPROVED BY