

Care Services Improvement Partnership **CSIP**

National Institute for
Mental Health in England



Valuing Involvement

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

**Guidelines for supporting communication
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 supporting guidelines are designed to address some of the recommendations made within the report. They set out some suggestions for effective communication for NIMHE and its staff to use when communicating to people from diverse groups who are involved within its work programmes.

The communication guidelines support the minimum standards for engaging diverse groups in NIMHE's work programmes.

Who are the Communication Guidelines for?

New NIMHE Staff and Volunteers

- All new staff should familiarise themselves with the communication 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 communication guidelines.

Existing NIMHE Staff and Volunteers

- Existing staff members should familiarise themselves with the communication guidelines.
- Existing staff should ensure that their work programmes make best use of the communication guidelines to support the involvement of people from diverse and often marginalised groups or communities.
- Any new work programmes should be developed using the communication guidelines.

People Sharing Their Expertise to Inform NIMHE's Work

- All people should be made aware of the expectations within the communication 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 work programmes should be expected to communicate their progress and developments in line with guidelines.
- All monitoring and evaluation of work programmes should include measures of effective communication.

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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)

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- 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 service user consultant previously with the Sainsbury Centre for Mental Health and a 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) made it clear that NIMHE needs to improve the way it communicates with service users and carers if it is to make involvement more inclusive. The principle suggested was “Will a member of the public who is experiencing mental illness for the first time be able to pick up the document and understand it?”

These guidelines should help all NIMHE staff and associates to think about how they can make information more accessible to different communities and groups. This may be for external communication with a target audience, or internal communication with individual service users and carers who are involved with NIMHE.

The Guidelines should be used alongside:

- the Minimum Standards for Engaging Diverse Groups and Communities – Making a Real Difference Resource Pack
- Guidelines for;
 - making events more inclusive
 - Ways of working with diverse groups and communities
- Recommendations for organising resources to support wider involvement
- The guidelines should also be read and used in conjunction with all of the documents within the ‘Making a Real Difference Involvement Resource Pack.’

There are no set rules for making information accessible for whole groups of people, because everyone has their own preferred ways of communicating. However, there are some general principles and specific advice that, if followed, should assist with communication. The guidelines are not intended to be either comprehensive or definitive, but instead offer:

- ✓ Some suggestions for making information easier to understand for everyone
- ✓ Some brief advice for better communication with specific communities and groups

Chapter 1 - Principles

When communicating with people, NIMHE staff and associates should:

- ✓ Remember that every person has their individual way of communicating.
- ✓ Explore preferences for information when people first get involved with NIMHE. This should be discussed during induction and recorded in the “involvement passport”. The effectiveness of communication should then be reviewed at a later stage
- ✓ Show sensitivity and flexibility when identifying and addressing communication needs of service users and carers.
- ✓ Not make assumptions about how people communicate but ask them. For example, not all Deaf people use British Sign Language
- ✓ Not let fear of getting things wrong put you off trying different ways of communication. Do your best, ask for feedback and learn from mistakes
- ✓ Be aware of possible “hidden” communications issues, for example, people who have difficulties reading and writing; or people from black and minority ethnic (BME) communities who may not be familiar with the written script of the language they speak.
- ✓ Where possible, offer a choice of formats; one person with reading difficulties may want an audio version, whereas another might prefer to get someone to read out a written version
- ✓ Many of the suggestions for one group may work with another, for example, some ideas for people with learning disabilities may transfer to people with dementia
- ✓ Remember that there is diversity within groups e.g. a young person may also have a first language which is not English
- ✓ Get people from the target audience involved in the design, production and dissemination of information and publicity from the start. There are many organisations that can provide expert help in communications, for example, local “People First” self-advocacy groups for people with learning difficulties. A proofing process is also helpful to identify any potential problems

Chapter 2 – General Guidelines

The following advice may help make information easier to understand for all citizens, including people from diverse communities and groups.

2.1 Text

- ✓ Use Plain English- simple language and short sentences with minimal jargon, abbreviations or acronyms
- ✓ Plan how to put across key messages. Cut out unnecessary detail and present ideas in a logical order
- ✓ Keep layout consistent within documents, and within regular publications like newsletters
- ✓ Use Arial font, size 12 point as a minimum (larger for people with visual impairments) , with good contrast between ink and paper, for example, black or blue print on a white or yellow background
- ✓ Avoid the excessive use of block capitals, italics, underlining and other text effects as these can be distracting
- ✓ Use a ragged right edge rather than fully justified text
- ✓ Use active and personal language which is direct- “you” and “we”
- ✓ Have a clear contents page and section headings
- ✓ Explain difficult words when they first appear, and have a word list at the back
- ✓ Make it clear if the reader has to do something, for example, highlight an address if they need to reply to an invitation
- ✓ When using information produced by another organisation, NIMHE needs to check that they have information in alternative formats so that this can be passed on if requested.

2.2 Pictures

- ✓ Photos, symbols and drawings can make writing easier to understand and more attractive
- ✓ However, it is important to judge the audience and type of image, so that the use of pictures is not seen as inappropriate or patronising
- ✓ Most people prefer photos and coloured pictures (but on electronic formats some people may want low graphics versions which are quicker to download)
- ✓ Be consistent with types of images used and don't use ones which are too complicated or abstract
- ✓ Put pictures beside the text not above or below it
- ✓ Pick one image per paragraph which best explains the main idea
- ✓ Pictures should be inclusive showing positive images of people from a range of communities
- ✓ Popular resources such as the "CHANGE" Picture Bank and "Widgit" can be helpful for ready-made images (be sure to check copyright conditions for use). For some examples see www.easyinfo.org.uk
- ✓ Taking photos to show specific buildings or people can be helpful, but make sure that consent is given for taking and using photos

2.3 Audio Visual Materials

- ✓ CDs are now easier and cheaper to produce in quantity than tapes. DVDs are also becoming more popular than videos
- ✓ However, if producing information for an individual, check their preferences
- ✓ Make sure that information will be clear to people watching or listening on a small screen or with small speakers (particularly if it is likely that people will be using a computer)
- ✓ As well as the "actors", small details such as music, clothes and decoration can be used to help make a video feel right for a particular community

Chapter 3 - Guidelines for Specific Groups and Communities

Below are some brief pointers for making information easier to use for some people. More details for engaging with diverse groups and communities is given in the Guidelines for Supporting Involvement, which covers:

Black and Minority Ethnic	Children and Young People
Older People	Gender
Primary Care	Personality Disorder
Lesbian, Gay, Bisexual or Transgender	Physical Disabilities or Sensory Impairment
Homelessness	Substance Misuse
Forensic and Criminal Justice	Rural Communities
Learning Disabilities	

3.1 Black and Minority Ethnic (BME) Communities (including people whose first language is not English)

- ✓ Where there is a known or likely need (for example, when promoting material around BME services or a major public consultation), information should automatically be made available in a number of the more common community languages These will vary between regions
- ✓ On request, any information available to the general public should be translated into any language. Contact details should be provided for such requests. If contact details are in another language, provision should be made for answering calls in this language. This could be via a community organisation or an answer phone message (though some people find recorded messages off putting and prefer to talk to someone).
- ✓ Access to interpreting services should be available when requested. This option should be promoted through the Race Equality programme or a on flyers for events
- ✓ Use translators and interpreters who are experienced and trained- preferably with some awareness of mental health terms. The NHS Language Line may help with one to one interpreting **(0800 169 2879)**
- ✓ Be aware that direct translations from English into other languages do not always work and that translations need to take cultural differences into account. For example, concepts such as advocacy or recovery may need to be explored in some detail

3.2 Children and Young People

- ✓ Be ready to try different methods of communication such as text messages and online chat rooms
- ✓ Make sure that material is suitable for the appropriate range of ages but bear in mind that children and young people of the same age may develop differently
- ✓ Use pictures, cartoons, photographs and videos to get across information
- ✓ Think about developing promotional materials such as posters and t-shirts to transmit brief key messages
- ✓ Think about using the media, celebrity role models and other young people to help convey messages and relate them to their expected audience

3.3 People With Learning Disabilities

- ✓ Many people with learning disabilities use 'easy read' documents, with simple text and pictures to illustrate what the text means
- ✓ Easy read versions of documents are often popular with people who do not have a learning disability as they can convey complex ideas in a clear way
- ✓ Use a clear layout for text, use bold text or speech boxes for key points
- ✓ Break writing into short chunks with plenty of space around text
- ✓ Start and finish sentences on the same page and avoid excessive punctuation
- ✓ Be consistent with use of the same words for important ideas even if it sounds repetitive
- ✓ Some people with learning disabilities may use Makaton (a basic signing and symbol system)

3.4 People Who Use Limited Verbal Language

- ✓ Be aware that people with high support needs may have ways of expressing themselves and making choices that are not immediately obvious to people who do not know them well
- ✓ This means it may be necessary to engage with people who live and work with a person to learn about how they communicate; or to work with the person's advocate
- ✓ A set of communication tools, for example, photos and objects of reference, may have been developed for an individual by the people who care for and know them well. This may provide an alternative or additional way of communication
- ✓ Working with people with very limited verbal language requires time and responsiveness to develop a real relationship where mutual understanding is possible
- ✓ Some people who have multiple impairments, for example, who are deaf and blind may require highly specialist support. This may be a trained personal assistant to help them with information or a liaison with a speech and language therapy service.

3.5 People with Visual Impairments

- ✓ People may require information in Braille or large print or audio versions
- ✓ If a person has a computer putting information in an email attachment or onto a disk or memory stick may allow them to adjust the font to a type which suits them best
- ✓ Use good quality matt paper (100gsm-130gsm) to avoid glare and stop the text showing through from one side to another
- ✓ Consider A3 format as opposed to A4 to make it easier to use large text and pictures

3.6 People Who Are Deaf or Have Hearing Impairments

- ✓ Many deaf people use British Sign Language (BSL) as their first language, not English. If so, ensure any information in English is simple and clear
- ✓ Ensure deaf people are aware that a BSL interpreter or lip speaker can be made available at meetings or events if required
- ✓ Have access to an induction loop in case this is required by someone with a hearing aid
- ✓ DVDs or videos can be used to translate publications into BSL
- ✓ Some deaf people are familiar with using text phones and Minicomms for telephone conversations. Type Talk can help with this through an operator- www.typetalk.org

3.7 People with Speech Impairments

- ✓ Give people time, don't try to guess what someone is trying to say or finish their sentences. Ask them to repeat it until you understand
- ✓ Check your understanding by reflective listening- repeating back the meaning but not the exact words of what a person has said
- ✓ If you are having problems understanding someone speaking you could offer them the option of writing it down

3.8 Older People

- ✓ Be aware that many older people may also have a visual or hearing impairment
- ✓ Use of language may be subtly different, for example, preference for the term "patient" instead of "service user"

3.9 People with Dementia

- ✓ Letting people with dementia talk at their own pace is important. Plan for fluctuations in concentration and include breaks when needed
- ✓ When working with people with dementia apparently small details of communication can be important, for example, recognising non verbal cues which reflect how a person really feels about something
- ✓ Put what people with dementia say in context and look for the meaning behind words, as mistakes with grammar and vocabulary are possible. Check that you have a shared understanding of the terms that people use without correcting them
- ✓ Direct questions may make people with dementia feel pressured as coming up with an immediate answer may be hard, which may make them feel embarrassed or frustrated.
- ✓ For more information see *Cantley et al "Listen to Us" (2005)*

Chapter 4 – Implementation

NIMHE needs to make information more accessible to a wider range of communities and groups across the whole range of media that it uses in its national programmes and Regional Development Centres. This includes reports, publicity material and presentations as well as phone systems, postal mail outs and papers for meeting.

In particular, the CSIP Knowledge Community, national and regional websites should meet standards of accessibility defined by organisations of people with disabilities which may include features such as audio commentaries and large text options.

The resource implications for NIMHE of developing and implementing an inclusive and accessible communications strategy will be explored in more detail in the *Recommendations for Organising Resources to Support Wider Involvement*. There will be resource requirements around finance, time and skills including:

- Staff development and training
- Accessing specialist support and advice, for example, translation services
- Equipment
- Design and production of material
- Building extra time into activities

It is important to think carefully about who and what the product is intended for as this will inform the design and formats to be made available. Drawing from existing expertise within NIMHE, for example, from the Race Equality Leads and other CSIP programmes, for example, Valuing People may be helpful.

Bibliography and References

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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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