

Care Services Improvement Partnership **CSIP**

National Institute for
Mental Health in England



Valuing Involvement

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

**Minimum Standards for 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 minimum standards are designed to address some of the recommendations made within the report. They set out the overarching principles expected of NIMHE and its staff when involving people within all of its work programmes.

The minimum standards begin to address how NIMHE can broaden the diversity of people involved and benefit fully from the expertise held within more marginalised groups and communities.

Who are the Minimum Standards for?

New NIMHE Staff and Volunteers

- All new staff should familiarise themselves with the minimum standards 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 in line with the minimum standards.

Existing NIMHE Staff and Volunteers

- Existing staff members should familiarise themselves with the minimum standards.
- Existing staff should ensure that their work programmes achieve the principles expected within the minimum standards, or have a plan in place to do so.
- Any new work programmes should be developed in line with the minimum standards.

People Sharing Their Expertise to Inform NIMHE's Work

- All people should be made aware of the expectations within the minimum standards 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 include plans to achieve the minimum standards.
- All NIMHE work programmes should provide regular feedback with regard to performance against the minimum standards.
- All monitoring and evaluation of work programmes should include measures of performance against the minimum standards.

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

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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

Background

One of the strongest messages from the “Making A Real Difference” consultation was the need for NIMHE to promote greater diversity and equality of service user and carer involvement. There is a real commitment from people working within NIMHE and CSIP to broaden the range of service users and carers who are actively involved within its work. There are also lots of positive examples in Regional Development Centres and National Programmes in engaging with diverse groups and communities. These Standards should help ensure that this good work is spread and built upon.

What do we mean by “diverse groups and communities”?

A person’s sense of “self” may be influenced by one or more factors such as gender, sexuality, race or age. People may also feel they share life experiences- positive or negative- with others who have a similar diagnosis or impairment the “Making A Real Difference” report and consultation identified some of the difficulties faced by particular groups when trying to take part in service user and carer involvement. These groups and communities included:

Black and Minority Ethnic Communities	Children and Young People
Older People	Women
Primary Care Service Users and carers	People with Personality Disorder and Their Carers
Lesbian/ Gay/ Bisexual/ Transgender Communities	People with Physical Disabilities or Sensory Impairment
People with Learning Disabilities	Substance Misuse service Users and Carers
Forensic/ Criminal Justice service users and carers	Rural Communities

However, there are many other things that impact on how individuals will experience mental distress and mental health services. These include education background, income status, employment and housing backgrounds.

NIMHE needs to be aware of potentially “hidden” or vulnerable groups and communities, such as Asylum Seekers, Travellers, people living in private sector care homes and people living in poverty, to make sure that they are not left out.

Inclusion is the right of everyone with personal experience of mental distress, regardless of diagnosis or length of experience. This includes people who do not use “services” because they have recovered, choose not to or are not eligible.

Chapter 1 - Purpose of the Minimum Standards

1.1 Principles

The Minimum Standards are a set of overarching principles which will:

- ✓ Apply to all NIMHE programmes and activities at national or regional level
- ✓ Acknowledge the rights of all service users and carers to work with NIMHE, whatever their background
- ✓ Be part of a culture change within NIMHE towards a more people-focused approach, built on mutual respect
- ✓ Require commitment and resources from all levels within NIMHE and CSIP

The Minimum Standards are not about:

- ✗ Putting people into boxes and treating them accordingly
- ✗ Saying any one group or community is more important than another
- ✗ Having a “tick box” or “politically correct” attitude to involvement
- ✗ Setting up complicated systems of representation or prescribing how to engage with people

The Minimum Standards should be used alongside:

- Guidelines for;
 - supporting communication with diverse groups and communities
 - making events more inclusive
 - ways of working with diverse groups and communities
- The Literature Review of Diversity in Service User and Carer Involvement in Mental Health
- Recommendations for Organising Resources to Support Wider Involvement
- The minimum standards should also be read and used in conjunction with all of the documents within the Making a Real Difference Involvement Resource Pack.

1.2 Underpinning Values

The Standards are based on:

- ✓ Participation on the basis of citizenship and social inclusion
- ✓ Promotion of recovery and self directed support
- ✓ Social model of disability

Chapter 2 – The Minimum Standards

2.1 The standards

When working with service users and carers from diverse groups and communities, NIMHE staff will:

- Standard 1 - Take a positive attitude to diversity, which celebrates different cultures and respects every person as an individual
- Standard 2 - Address the structural barriers to involvement faced by different groups and communities, including the impact of discrimination
- Standard 3 - Provide practical and personal support to enable the participation of service users and carers from a wider range of backgrounds
- Standard 4 - Make information more accessible to the individuals, groups and communities with whom they are working
- Standard 5 - Make events and activities inclusive of the individuals, groups and communities with whom they working
- Standard 6 - Develop more flexible and creative ways of engaging different groups and communities
- Standard 7 - Show its commitment as an organisation to mainstreaming equality and diversity of service user and carer involvement in its corporate policies, procedures and workforce
- Standard 8 - Build upon existing networks, resources and positive practice
- Standard 9 - Develop mutually supportive relationships with local communities and stakeholder groups
- Standard 10- Ensure its systems of service user and carer involvement support the needs of diverse groups and communities

2.2 Putting the Minimum Standards into Practice

Standard 1 - Taking a Positive Attitude

- NIMHE will look at the different strands of equalities in an holistic way, recognising that diversity is a complex issue, and that there is great diversity within groups
- NIMHE will celebrate the diversity of cultures and communities with whom it works, and learn about how cultural norms may influence experience of mental health problems.
- It will respond to the needs that individuals have with regard to involvement without viewing equality as “treating everyone the same
- NIMHE will tackle stigma and discrimination in all its form. It will challenge cultural assumptions, for example that children are not able to contribute in a responsible manner, or that all older people are frail

Standard 2 - Acknowledging Structural Barriers and Discrimination

- NIMHE will recognise that service users and carers from particular groups and communities may often have experienced discrimination. This may be from mental health services or other service users and carers, including from NIMHE itself, as well as from society
- NIMHE will support the needs of groups who have experienced such oppression to have safe spaces to meet and develop in their own ways whilst encouraging two way links with mainstream user and carer involvement networks
- NIMHE will show awareness of power imbalances and act according, for example, by using language sensitively with regard to gender, by having a service user or carer from a minority community as chair of a meeting instead of a professional, and valuing different types of knowledge equally
- NIMHE will not replicate barriers to participation that exist within society and care services, for example by not creating lots of bureaucracy or divisions between client groups

Standard 3 - Providing Practical and Personal Support

- NIMHE will ensure there is emotional support available for individuals. When a sensitive topic such as self harm or abuse is being discussed, thought should go into how distress can be worked through
- In some communities with less awareness of mental health, it may be necessary to do some groundwork before active participation is a possibility. For example, many people from Black and Minority Ethnic communities may not be aware that they are a “carer”. Other groups, for example, prisoners may never have been asked for their opinions

Standard 4 - Making Information More Accessible

- Service users and carers with different communication needs should receive information at the right time in a format that is as accessible for them
- NIMHE staff and associates should be aware of communication issues, and know how information can be provided to different groups and communities

For more detail on how to make information easier to understand for people, see *“Supporting Communication with Diverse Groups and Communities”*, *Making a Real Difference Resource Pack*

Standard 5 - Making Events and Activities More Inclusive

- NIMHE needs to ensure that venues are appropriate and accessible to the communities they serve
- The content and format of meetings and events also needs to be tailored to the needs of service users and carers whom NIMHE seeks to involve

For more detail on how to make events more accessible, see; *“Guidelines for Making Events more Inclusive”* *Making a Real Difference Resource Pack*

Standard 6 - Creative and Flexible Ways of Engaging Groups and Communities

- NIMHE needs to use a wider range of approaches than traditional meetings or consultations in order to get views from as many service users and carers as possible
- This includes more informal events, going to where communities meet already, and using focused approaches to work with specific groups

For more detail on different ways of engaging, see;
Ways of Working with Diverse Groups and Communities - Making a Real Difference Resource Pack

Standard 7 - Organisational Commitment

- NIMHE staff and associates who work with service users and carers should have the skills and confidence to work with people from a wide range of backgrounds
- Equality and diversity training should be available for NIMHE staff and associates, including service users and carers who have a key role in governance or regional networks, to fill any skills gaps
- Senior managers within NIMHE should show leadership in promoting diversity of service user and carer involvement and prioritise resources accordingly
- When developing policies and procedures that affect service user and carer involvement, the potential impact on diverse groups and communities should be considered
- NIMHE should aim to set an example of diversity through its own recruitment and workforce development processes
- Service users and carers should know what to do if they feel they have been treated unfairly by NIMHE staff, or other service users or carers, because of their race, gender, sexuality, age, faith or disability

Standard 8 - Building on Positive Practice

- NIMHE will work with established mental health networks and organisations that work with service users and carers from different communities and groups
- NIMHE will support organisations and networks which work within communities and groups on other issues to develop access to mental health participation
- NIMHE will respect the independence of such networks or organisations, and help build their capacity with resources including access to knowledge, information and decision making systems within NIMHE
- NIMHE will act on things that communities and groups have already identified as important and not keep asking the same questions
- NIMHE will make use the diverse skills and lived experiences of its own staff as well as users and carers in their networks.
- NIMHE will make stronger links to other CSIP programmes, and share learning across regions. It will work with other organisations who are also looking to promote equality and diversity of service user and carer involvement

Standard 9 - Developing Relationships with Communities and Stakeholder Groups

- NIMHE will build trust with people who may have negative experiences of statutory organisations. They can do this by developing personal relationships with community leaders or development workers and by having a visible presence at community events
- NIMHE will give communities enough time for proper consultation, build their capacity to work on the issues that are important to them and not always imposing a pre-determined agenda
- NIMHE will work directly with service users, carers and grass roots groups as well as larger voluntary organisations, community leaders or workers, to ensure a full range of views are accessed.

Standard 10 - Systems to Support Involvement of Diverse Groups and Communities

- NIMHE will monitor the profile of service users and carers who get involved or respond to adverts for involvement, explaining what the data will be used for and respecting confidentiality or anonymity as far as possible
- NIMHE will find out how service users and carers from different backgrounds feel about the way they are treated
- If particular communities or groups are shown to be underrepresented within NIMHE, or appear to be having negative experiences, remedial action will be taken
- All NIMHE programmes should be able to show that they have considered how their work impacts on different groups and communities and how those communities are involved.
- NIMHE's regional and national networks and forums of service users and carers will show due regard for the profiles of their members and demonstrate how they are including diverse groups and communities.
- Particular attention will be paid to ensuring that decision making systems are fair, accessible and accountable to diverse communities and groups. This includes developing the leadership skills of people from different backgrounds enabling them to take part fully.

Chapter 3 – Monitoring and Evaluation Indicators

The following are a set of potential indicators for the monitoring and evaluation of the **minimum standards**. These need to be discussed and refined. In particular, thought needs to be given as to how to measure some of the more abstract concepts such as awareness of discrimination and power dynamics.

Standard	Action	Indicator
1. Taking A Positive Attitude	<ul style="list-style-type: none"> a) NIMHE will take an holistic approach to diversity and recognise complexity b) Celebrating cultures and learning about diversity c) Responding to individuals needs d) Challenging stigma and assumptions 	<ul style="list-style-type: none"> • Approach shown through user and carer involvement strategies, projects and programmes • Articles in news bulletins marking community festivals • Analysis of feedback on experience of service users and carers from different backgrounds gathered from involvement monitoring and evaluating tools • Response and feedback concerning any attitude change shown as a result of participation in training – staff involvement training pack – involving diverse groups exercise.
2. Acknowledging Barriers and Discrimination	<ul style="list-style-type: none"> a) Recognising the effects of discrimination b) Creating safe spaces for people from groups and communities to meet, and links to mainstream user and carer groups c) Acknowledge and address issues of power imbalance d) Avoiding replication of existing barriers 	
3. Practical and Personal Support	<ul style="list-style-type: none"> a) NIMHE will ensure there is emotional support available for individuals b) In some communities with less awareness of mental health, it may be necessary to do some groundwork before participation 	<ul style="list-style-type: none"> • Audit of monitoring and evaluation products - End of Involvement Questionnaire and Involvement Plans • Content and impact of service user/ carer involvement programme delivery

4. Making Information Accessible	<p>a) Service users and carers with different communication needs should receive information at the right time in a format that is accessible for them</p> <p>b) NIMHE staff and associates should be aware of communication issues, and how information can be provided</p>	<ul style="list-style-type: none"> • Audit of monitoring and evaluation products- End of Involvement Questionnaire and Involvement Plans • RDC and National Communications Strategies in place.
5. Making Events more Inclusive	<p>a) NIMHE needs to ensure that venues are appropriate and accessible to the communities they serve</p> <p>b) The content and format of meetings and events also needs to be tailored to the needs of service users and carers</p>	<ul style="list-style-type: none"> • Agreement and use of accessibility checklists e.g. Social Care Institute for Excellence (SCIE) or the Disability Rights Commission (DRC) • Event or meeting feedback forms
6. Creative and Flexible Ways of Engaging Groups and Communities	<p>a) NIMHE needs to use a wider range of approaches than traditional meetings or consultations in order to get views from as many service users and carers as possible</p> <p>b) This includes more informal events, going to where communities meet already, and using focused approaches</p>	<ul style="list-style-type: none"> • Audit of types and frequency of RDC and national activities aimed at engaging service users or carers from diverse communities plus numbers involved • Analysis of demographics of service user or carer input into other NIMHE or CSIP work • Qualitative feedback from NIMHE staff, service users, carers and the public on how successful these approaches are
7. Organisational Commitment	<p>a) NIMHE staff and associates who work with service users and carers should have the skills and confidence to work with people from a wide range of backgrounds</p> <p>b) Equality and diversity training should be available for NIMHE staff and associates, including service users and carers who have a key role in governance or regional networks, to fill any skills gaps</p> <p>c) Senior managers within NIMHE and CSIP should show leadership in promoting diversity of involvement and prioritise resources</p>	<ul style="list-style-type: none"> • Requirement of job descriptions and person specifications • Monitor through personal development plans or performance management system, for example, the Key Skills Framework (KSF) • Rolling delivery of specialist training commissioned or provided in house either as addition to effective generic service user and carer involvement training or as part of wider equality and diversity strategy • Profile and resource allocations detailed through RDC work programmes and corporate publicity

	<p>d) When developing policies and procedures that affect service user and carer involvement the potential effect on diverse groups and communities should be considered</p> <p>e) NIMHE and CSIP should aim to set an example of diversity through its own recruitment and workforce development processes</p> <p>f) Service users and carers should know what to do if they feel they have been treated unfairly by NIMHE staff, or other service users or carers, because of their race, gender, sexuality, age, faith or disability</p>	<ul style="list-style-type: none"> • Inclusion in upcoming “Equalities Bill Public Sector Duties” impact assessments. • Content of policy documents, protocols etc • Application of “Positively Diverse, Improving Working Lives” • Recognition as positive Employer by Stonewall plus Disability kite marks • Use of same procedures as CSIP employed staff
<p>8. Building on Positive Practice</p>	<p>a) NIMHE will work with established mental health networks and organisations that have the trust of service users and carers from different groups and communities</p> <p>b) NIMHE will support organisations and networks which work within communities and groups on other issues to develop access to mental health participation</p> <p>c) NIMHE will respect the independence of such networks or organisations while supporting them with resources including access to information and decision making systems within NIMHE</p> <p>d) NIMHE will act on things that communities and groups have already identified as important and not keep asking the same questions</p>	<ul style="list-style-type: none"> • Strategies and policies make reference to key partners for specific groups and communities • Products and events delivered by or in partnership with other organisations • Pre and post Making a Real Difference snapshot of awareness of NIMHE • Evidence of these organisations taking up mental health issues, for example, writing articles or policy references • More input from service users, carers and the public from these groups and communities • Development and maintenance of long term and close working relations with partner organisations and networks • Levels of investment, for example, time, administration support, funding or capacity building given to partners

	<p>e) NIMHE will make use of the diverse skills and lived experiences of its own staff as well as service users and carers in their networks.</p> <p>f) NIMHE will make stronger links to other CSIP programmes, share learning across regions and work with local organisations who are also looking to promote equality</p>	<ul style="list-style-type: none"> • Feedback from NIMHE and partners concerning experiences of co-working • Better co-ordination of consultation and less duplication of feedback or involvement • NIMHE staff being familiar with key service user and carer issues for groups and communities (from the literature review of diversity in service user and carer involvement in mental health, plus key policies) • Mapping of available skills and interests in RDCs • Opportunities for NIMHE staff from all positions to develop skills in working with diverse communities, for example, through employee volunteering, job shadowing, mentoring or secondment. • Evidence of partnership working and dissemination of learning
<p>9. Developing Relationships with Communities and Groups</p>	<p>a) NIMHE staff need to build trust with people who may have negative experiences of statutory organisations.</p> <p>b) NIMHE need to give communities enough time for proper consultation and to build their capacity to work on the issues that are important to them</p> <p>c) Working directly with service users and carers from communities</p>	<ul style="list-style-type: none"> • RDC action plans to reach out to communities. • Evidence of visits to community venues and contact with key individuals. • Quality of response to consultation and input into work programmes • Resources made available to community groups • Research into community perceptions of their local RDC and experience of co-working • Contacts and feedback from service users and carers

<p>10. Ensure Its Systems of Service User and Carer Involvement Support the Needs of Diverse Groups and Communities</p>	<p>a) NIMHE should monitor the profile of service users and carers who get involved or respond to adverts for involvement in a way that does not feel too formal or too time consuming</p> <p>b) NIMHE also needs to find out how service users and carers from different backgrounds feel about the way they are treated</p> <p>a. If particular communities or groups are shown to be underrepresented within NIMHE or appear to be having negative experiences remedial action should be taken</p> <p>b. All NIMHE programmes should be able to show that they have considered how their work impacts on different groups and communities and how those communities are involved</p> <p>c. NIMHE’s regional and national networks and forums of service users and carers should be aware of the profiles of their members and demonstrate how they are including diverse groups and communities.</p> <p>d. Particular attention will be paid to ensuring that decision making systems are transparent, fair and accessible to diverse communities and groups.</p>	<ul style="list-style-type: none"> • Audit of monitoring and evaluation tools - “Fair Access Form” • Audit of monitoring and evaluation tools – “End of Involvement Questionnaire” and “Involvement Plans” • Including service users and carers in CSIP equalities monitoring process • Development, monitoring and evaluation action plans (with input from relevant group or community) plus feedback and dissemination of outcomes • Evidence from work programmes and performance management processes • Build into contracts for forums and networks and tender applicants to demonstrate how will be achieved • Forums and networks to develop strategies to secure diversity and equality which are open for public scrutiny • Evidence of targeted recruitment, development of subgroups or liaison with external networks. • Delivery of leadership and effective involvement training to members of different groups and communities
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Regional Development Centres and National Programmes need to embed the minimum standards in the strategies, action plans and operational policies which they adopt in response to the overall Making A Real Difference project. Further guidance on how this can be done will be given in “*Recommendations for organising Resources to support Wider Involvement*” *Making a Real Difference Resource Pack*.

Chapter 4 - Methodology

The Minimum Standards paper is based on:

- An audit of current practice within NIMHE and CSIP
- Interviews with key stakeholders who work for or with NIMHE and CSIP
- A Literature Review of Diversity in Service User and Carer Involvement in Mental Health (to be published by Staffordshire University, 3rd November 2006)
- A scoping of similar policies and standards within other organisations

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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 of the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.

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