

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**

**Recommendations for organising resources
to support wider involvement**

A Product of the Making a Real Difference Project

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 document is designed to address recommendations made within the report. It explores the resource implications NIMHE and its staff will need to consider when planning to increase the diversity of people involved within all of its work programmes.

The resource implications paper begins to address how NIMHE can support the commitment to broaden the diversity of people involved and benefit fully from the expertise held within more marginalised groups and communities.

Who needs to consider the Resource Implications?

Regional Development Centre Directors

- All Directors should be aware of the potential implications of broadening the diversity of people groups and communities involved in the work of NIMHE.
- Directors should expect realistic resources to be built into headline management plans (HMP's) to support involvement and should encourage their staff to do this.

New NIMHE Staff and Volunteers

- All new staff should use the resource implications paper to guide them in the development of all new work programmes.

Existing NIMHE Staff and Volunteers

- All existing staff should consider the resource implications of broadening the diversity of people involved in their work programmes.
- All existing staff should use the resource implications paper to guide them in the development of all new work programmes.

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

- All NIMHE work programmes should be expected to highlight involvement resources within their Headline Management Plans.
- All NIMHE work programmes should provide regular feedback with regard to performance against the HMP's. This should include financial updates regarding involvement.

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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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- 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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- Primary Care: Birmingham, 29th November 2006. Focus group facilitated by Pen Mendonca
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Introduction

The *Making A Real Difference* Report highlighted the need for NIMHE to improve the way it works with people from diverse communities and background in its service user and carer involvement activities.

All of the recommendations and products of the *Making A Real Difference* project are important.

The underlying principles of this document, based on the Minimum Standards for working with diverse groups and communities are the commitment to:

- Mainstream diversity of service user and carer involvement into NIMHE and CSIP's existing structures and activities
- Provide practical support to ensure different communities and groups have real influence across NIMHE at all levels
- Develop partnership working with external networks and organisations with experience of working with diverse communities and groups

Resource limitations were cited as a barrier to involving diverse groups and communities in several responses from national programmes and Regional Development Centres. Implementing the products from *Making A Real Difference* in a way that genuinely engages users and carers from all backgrounds means changing the way CSIP works as an organisation, which has major resource implications. These may include direct financial costs such as holding an event with a particular community or putting publicity material into different formats. There are also indirect costs such as staff time, admin support, training and development.

The *Making A Real Difference* products are being implemented in a climate of organisational change and financial pressures within CSIP. It is also recognised that CSIP has already committed significant resources to developing its service user and carer involvement programmes. Therefore, the focus of this paper is on making the most effective use of existing resources, with a more strategic focus on strengthening the involvement of diverse communities and groups, and a more rigorous evaluation of how well this is working.

It is also important to remember that many of the Minimum Standards for Involving Diverse Groups and Communities relate to the attitudes of CSIP staff and the culture of the organisation. Implementation of these recommendations is not necessarily about money.

Chapter 1 - Financial Implications of Strengthening Diversity of Service User and Carer Involvement

It is not possible to put exact costs on how much it will cost to implement the recommendations on diversity across the whole of the *Making A Real Difference* project. The paper '**Resource Implications of Valuing Involvement**', gives a "guesstimate" of 7%-8% of an overall programme budget as necessary to support involvement. It is likely that these levels of investment will cover only the costs of "generic" involvement and that systematic efforts to increase diversity of involvement will add to this percentage. It may be that, to have any real impact on broadening engagement, resources, commitment and effort will need to be targeted at outreach work with those groups that have been historically most marginalised. Addressing this structural inequity in involvement may therefore have to be prioritised over other activities.

Working with diversity will have an ongoing and long term impact on resources. As ways of engaging previously excluded communities and groups become more effective, more service users and carers will become involved and costs may grow, particularly at RDC level. Investment could, in effect, be limitless. Ultimately, each RDC will have to make its own decisions on how it organises resources for involvement to secure the involvement of different communities.

1.1 Resource Implications of the Minimum Standards for Involving Diverse Groups

Standard	Supporting Actions and Requirements	Resource Implications
1. Take a positive attitude to diversity, which celebrates different cultures and respects every person as an individual	Holding and contributing to cultural events Building awareness into everyday practice and culture	Low: <ul style="list-style-type: none"> • Limited finance and staff time
2. Address the structural barriers to involvement faced by different groups and communities, including the impact of discrimination	Providing a "safe space" for service users and carers from excluded communities and groups to share experiences and engage with mainstream networks	Low: <ul style="list-style-type: none"> • Limited meeting costs and facilitation time for different groups and communities

<p>3. Provide practical and personal support to enable the participation of users and carers from a wider range of backgrounds</p>	<p>Provision of emotional support for service users and carers to manage distress around sensitive issues</p> <p>Awareness raising of mental health issues and development of service user and carer involvement skills in different communities and client groups</p>	<p>Medium:</p> <ul style="list-style-type: none"> • Identifying appropriate workers to provide support • Potential need for targeted training and capacity building programmes and sessions
<p>4. Make information more accessible to the individuals, groups and communities with whom they are working</p>	<p>Producing information that is relevant to different groups and communities in formats and languages that are accessible and disseminating through appropriate networks</p> <p>Staff awareness of how to meet information needs</p>	<p>High:</p> <ul style="list-style-type: none"> • Interpreting costs for meetings and events • Cost and time for production of information in accessible formats and community languages including design input from service users and carers from relevant backgrounds • Costs of publicity in community media • Specialist communications training for key staff and general training for other staff • Staff time to provide appropriate information
<p>5. Make events and activities inclusive of the individuals, groups and communities with whom they working</p>	<p>Using accessible community venues</p> <p>Personal support for users and carers at meetings/ events</p>	<p>Medium:</p> <ul style="list-style-type: none"> • Potentially higher venue costs if necessary to meet access requirements • Equipment costs, for example, induction loops • Training for CSIP staff on meeting access needs • Costs of child or other caring expenses and specialist support such as language therapists or personal assistants • Time built into events and activities to allow for support for genuine participation

<p>6. Ensure its systems of service user and carer involvement support the needs of diverse groups and communities</p>	<p>Using a range of creative ways to engage with diverse groups and communities beyond traditional meetings or consultation processes</p>	<p>High:</p> <ul style="list-style-type: none"> • Piloting and evaluating different ways of working including informal approaches • Paying for consultancy or sessional workers to engage particular communities
<p>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</p>	<p>CSIP staff and associates to have relevant skills and knowledge to work with people from all backgrounds</p> <p>Involving service users and carers from diverse backgrounds in developing and delivering corporate policies and procedures</p> <p>Leadership and commitment</p> <p>Workforce reflective of diversity</p>	<p>Medium</p> <ul style="list-style-type: none"> • Equality and diversity training to meet any identified skills gaps • Payment of fees and expenses for input plus meeting arrangements, for example, for taking part in recruitment or selection • Time of senior managers • Strengthened recruitment and staff and volunteer development processes, for example, adverts in community press or mentoring arrangements
<p>8. Build upon existing networks, resources and positive practice</p>	<p>Partnership working with established networks and organisations</p> <p>Work across CSIP and NIMHE work streams and programmes</p>	<p>High:</p> <ul style="list-style-type: none"> • Time to identify links and build relationships • Resources to support capacity building in partner organisations such as finance, administration support, skills transfer , time and information • Time and financial commitment from other programmes
<p>9. Develop mutually supportive relationships with local communities and stakeholder groups</p>	<p>Outreach work, for example, attending community events, work placements or sessional development work</p>	<p>High</p> <ul style="list-style-type: none"> • Resource transfer to grass roots organisation to build capacity for engagement • Time for representatives from communities to undertake proper consultation

<p>10. Ensure its systems of service user and carer involvement support the needs of diverse groups and communities</p>	<p>Monitoring and evaluation of equal opportunities for involvement activities</p> <p>Involvement of service users and carers from diverse communities and groups in governance and decision making</p>	<p>Medium</p> <ul style="list-style-type: none"> • Time and money for routine data collection and analysis systems plus more detailed qualitative work to monitor outcomes of Diversity Standards implementation on service user and carer experiences • Recruitment leadership training, ongoing support and expenses for individuals involved
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Chapter 2 - Organising Resources Effectively

The following are suggestions for how CSIP and NIMHE could make best use of resources available to support diversity of service user and carer involvement.

2.1 Stronger Links With Other Work streams and Programmes

Service user and carer involvement does not exist in a separate “silo”. It is the responsibility of all NIMHE and CSIP staff to support involvement in their own work streams. This is especially true where other programme leads may have skills, experience and resources which can complement those of service user and carer leads. These may include NIMHE work streams, such as Personality Disorder, Women’s Mental Health and Race Equality. It also includes CSIP programmes such as Primary Care, Health and Criminal Justice, Valuing People and programmes for Younger and Older People. The “Having A Voice” project gives an opportunity to co-ordinate participation across CSIP.

Administration support should be available to support this collaboration. CSIP should encourage agreement for co-delivery and co-funding of involvement activities across programmes and work streams at national and regional level in its Headline Management Plans process.

2.2 Building Diversity Into the Whole *Making A Real Difference* Project

Engaging different groups and communities is not a stand alone activity. All the products of the *Making A Real Difference* Work Project are important to help NIMHE and CSIP implement the original HASCAS report recommendations. Appendix 1 gives an indication of what the diversity implications are for each of the products from the other work groups, and associated resource considerations. RDC and national programme plans for implementing Making A Real Difference should build diversity of involvement into all actions

Working With Strengths

A self assessment of RDCs current engagement with diverse groups and communities showed different perceived strengths and weaknesses. There were some communities and groups, for example people with physical or sensory impairment, where all regions indicated difficulties. There were also examples, such as people from rural areas of people with personality disorder, where some regions have examples of positive practice whereas others do not. Although the self assessment return rate from national programmes was low similar variation in how well different groups and communities are included are apparent. Progress in working with people from diverse backgrounds will be measurable from the monitoring and evaluation processes.

*Regional Development Centres with an identified strength or interest in working with a particular community or group could take a “lead role”, for example, in involving users and carers from that background in national consultation processes, or making links to national networks. **This does not mean that other regions do not have a responsibility to work with service users and carers from all groups and communities.***

RDCs and national programmes with identified strengths in working with groups and communities should share that expertise with others, for example, through dissemination in the Service User and Carer Leads Network, or establishing joint projects or reference groups.

Partnership With Other Organisations

NIMHE and CSIP should seek to develop partnerships with other organisations and networks that are seeking to strengthen diversity in service user and carer involvement. This may add value to NIMHE’s involvement activities and maximise resource potential in engaging with specific groups or communities. Joint working can be at local, regional and national level with

service user and carer groups, voluntary organisations, or other statutory sector organisations.

In particular, opportunities for partnership working on diversity may exist with the new LINKS arrangements for patient and public involvement (PPI) and in the requirement for public sector organisations to involve stakeholders in implementation of the Equality Duty legislation, for which some providers are setting up reference groups consisting of people from relevant communities and backgrounds. Other organisations with a Health and Social Care focus which are working to improve diversity and equality of service user and carer involvement include Together, through its regional and national networks, SCIE through the Social Perspectives Network, and the “Shaping Out Lives” national user network

Chapter 3 - Putting the Minimum Standards Into Practice

As part of their overall Action Plans for implementing all the *Making A Real Difference* products, RDCs and National Programmes need to develop a strategy which shows how they will improve the diversity of service user and carer involvement and build this into their service user and carer involvement operations policy. Different regions and work streams will do this in their own way, however, consideration when developing strategies and policy should be given to:

1. **Statement of Principles and Values.** This should reflect the minimum standards on supporting diversity of service user and carer involvement
2. **Establishing a Baseline.** Self- assessment of how well different communities and groups are engaged with networks and programmes, for example, from questionnaires to members of networks, data on attendance at events
3. **Mapping of Resources.** Staff and associate skills, existing links with community groups and potential for partnership working with other organisations
4. **Resource Availability.** Commitment of budgets, staff and administration time
5. **Action Plans for Strengthening Diversity of Involvement.** Procedures and processes for supporting people from different communities and groups to participate in:
 - Governance
 - Communication and information
 - Corporate policies and procedures
 - Work programmes
 - Service user and carer networks
6. **Monitoring and Evaluation of policy/strategy.** Arrangements for review.

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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Diversity Resource Implications for Other Work Groups

Work Group	Product or Activity	Resource Implications
1- Purpose of Involvement and Communications	Corporate Vision Statement on Purpose of Involvement National and Regional Communications Strategies	<ul style="list-style-type: none"> • Making documents available in a range of accessible formats and community languages • Making strategy documents available in a range of accessible formats and community languages • Producing regional and national promotional material in a range of accessible formats and community languages • Disseminating publicity information through community networks and media • Develop innovate ways for service users and carers from different backgrounds to access information, for example, interactive websites and video conferencing
2- Culture	Good practice standards for work programmes and operations policy for RDCs Staff training material and induction pack	<ul style="list-style-type: none"> • Making documents available in a range of accessible formats and community languages as required by those service users and carers who become involved • Support for service users and carers from diverse backgrounds to co-deliver training, for example, paying a local community group and making training material accessible
3- National Networks	Establishment of national NIMHE user and carer forums, providing representation for NIMHE Programme Board	<ul style="list-style-type: none"> • Support for service users and carers from diverse backgrounds to take part in forums, for example, recruitment material in range of languages and formats, provision of personal assistants at meetings and awareness training for other forum members • Outreach work to engage organisations working with diverse communities and client groups to create links by which service users and carers from different backgrounds can influence the national forums

Work Group	Product or Activity	Resource Implications
4- Engaging Diverse Groups	SEE MAIN DOCUMENT	SEE MAIN DOCUMENT
5- Support for Involvement	<p>Good Practice Guidelines for Commissioners concerning how they can support the development of local service user and carer groups</p> <p>Induction programmes for service user and carer representatives.</p> <p>Database of appropriate training available for service users and carers.</p> <p>Procedures to support service user and carer representatives to gain the support, skills and training needed to successfully move from one role to another, that is, regional representative to national representative.</p>	<ul style="list-style-type: none"> • Working with local commissioners to support the development of opportunities for involvement for people from diverse backgrounds, building on the work of existing mental health service user and carer groups and community organisations. This may include equality and diversity awareness raising for commissioners and service user and carer groups or making guidelines available in accessible formats and languages • Making induction resources available in accessible formats and languages • Inclusion of material on equality and diversity in all induction packs and programmes • Database to include information on where equality and diversity training is available • Provision of equality and diversity training if it is not available elsewhere • Database to be made accessible and promoted to different communities and client groups • Information, processes and supporting material be made accessible and promoted to different communities and client groups

Work Group	Product or Activity	Resource Implications
6- Finance	Valuing Involvement payment and reimbursement policy guidelines to cover payment of fees and expenses to service users and carers	<ul style="list-style-type: none"> • Information, processes and supporting material on how payments will be made to be accessible and promoted to different communities and client groups • Budget provision to be made for increased payment of service user and carer expenses and fees as more people become involved including people who may have higher support needs
7- Monitoring and Evaluation	<p>Service user and Carer led monitoring systems</p> <p>Individual “involvement passports” for active service users and carers</p>	<ul style="list-style-type: none"> • Identifying equality and diversity issues from evaluation of involvement systems and addressing any areas of concerns • Identifying and meeting information and other support needs which service users and carers may have.

