Valuing Involvement

Strengthening Service User and Carer Involvement in NIMHE

Policy for involving service users and carers

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 policy is designed to address some of the recommendations made within the report. It sets out how the commitment NIMHE has made to involve people with experience of mental health problems and their friends and families who care for them, will be delivered within all of its work programmes.

This policy is the concern of all NIMHE staff and anyone associated with the delivery of any work undertaken by or on behalf of NIMHE.

RATIFYING BODY …………………………………………………………………………

DATE RATIFIED ………………………………………………………………………

NEXT REVIEW DATE …………………………………………………………………

TO BE APPROVED BY …………………………………………………………………
### Acknowledgements

The Policy for Involving Service Users and Carers was developed and written by Diane Bardsley on behalf of the Making a Real Difference Project.

This document was produced by the South West ‘Making A Real Difference Working Group’ which included Service Users and Carers.

Diane Bardsley (Project Lead)  
Lucy Pearce  
Emma Laughton  
Louise Neville  
David Dixon  
Sally Luxton

Gwen Butcher  
Eddie Godfrey  
Mark Norman  
David Pennington  
Julie Armstrong

The make up of the steering group was as follows:

<table>
<thead>
<tr>
<th>Designation</th>
<th>% of group</th>
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<tbody>
<tr>
<td>CSIP Staff</td>
<td>30%</td>
</tr>
<tr>
<td>People with experience of using mental health services</td>
<td>40%</td>
</tr>
<tr>
<td>People with experience of caring</td>
<td>30%</td>
</tr>
</tbody>
</table>

We wish to thank for their support and advice:

Paddy Cooney  
Kate Schneider  
Steve Onyett  
David Goodban  
Linda Parker  
Ross Hughes

John Wood  
Karen Stuckey  
Liam Gilfellon  
Sally Prescott  
Pam Taylor

The South West Making a Real Difference consultation event was attended by approximately 110 people.

This document was informed by the expertise of people from the following groups and organisations:

- Advocacy in Somerset  
- Anchor Project  
- Avon & Wiltshire Mental Health Partnership NHS Trust  
- Bath and North East Somerset Council  
- Bath and North East Somerset Primary Care Trust (PCT)  
- Battle Against Tranquillisers (BAT)  
- Bristol PCT  
- Bwerani Multicultural and Inclusive Resource Library  
- Carers and Relatives Mutual Support (CARMS)  
- Carers Support North Wiltshire  
- Care Services Improvement Partnership (CSIP) North East, Yorkshire and Humber Regional Development Centre  
- CSIP South West Making a Real Difference Workgroup  
- CSIP South West Black and Minority Ethnic (BME) Network  
- CSIP South West Mental Health Reference Group for Avon, Gloucester & Wiltshire  
- CSIP South West Mental Health Reference Group for Devon & Cornwall
We would also like to say thank you to the service users and carers who did not necessarily belong to any of the above groups but who also contributed to this document.
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Introduction

The Care Services Improvement Partnership (CSIP) and the National Institute for Mental Health (NIMHE) work with people and services in the health, local government, public, voluntary and private sectors. The aim is to improve services and the health and well being of people in England. Through CSIP’s Regional Development Centres and programmes of work, we help people to put health and social care policy into practice, and help to resolve local challenges in improving health and social care.

This policy sets out how CSIP and NIMHE will promote and govern the participation and involvement of people who use services, and people who support them, in all aspects of its work.

Corporate Policy and Vision Statement

The purpose of involvement is to empower people with experience of mental health problems, and their family and friends, to work in partnership to:

- create and deliver services that promote mental health and well being, offer optimism and hope and support individuals to manage or overcome their mental health problems.
- shift the balance of power, challenge stigma and discrimination, respect and value diversity and promote social inclusion and active citizenship.

Principles

This policy is underpinned by the following principles:
- empowering and supporting people to manage their own mental health.
- creating services that promote hope and optimism and support people to achieve mental well being.
- engaging people with direct experience in the design, development, delivery and monitoring of services.
- changing the balance of power.
- respecting diversity.
- challenging inequalities and promoting active community engagement.

Values

The principles are supported by the following values:
- when service users and carers become involved with NIMHE, their health and well being comes first;
- service users and carers have a wide range of valuable knowledge, skills and expertise which will be drawn upon;
- service users and carers have a key role to play in the work of NIMHE, and to help to develop good practice;
- the involvement of a diverse range of service users and carers who reflect the community is essential for the relevance and responsiveness of NIMHE;
- service users and carers will be appropriately trained, supported and rewarded for their contribution to the work of NIMHE.
Purpose

This policy has been developed in order to ensure that:

- service user and carer involvement is sought in all work programmes
- all work will follow the principles of good practice;
- our work demonstrates respect for all participants, and promotes their dignity, wellbeing and effectiveness if our practice falls short of these principles, we will reflect on this, learn, and try to improve.
Chapter 1 - Operational Policy

1.1 Scope

This policy addresses the effective participation and engagement of Service Users and Carers within the Regional Development Centres under the following headings:

1. Strategy and Governance
2. Work Programmes
3. Procedure for Involving Service Users and Carers
4. Communications
5. Recruitment of Staff
7. Staff Development
8. Review of CSIP Policy

1.2 Good Practice

This policy highlights the importance of the principles identified in the Good Practice Guidance. In summary these principles are that as an organisation, and as individuals we should endeavour to:

- be clear
- be inclusive
- treat people equally
- have a positive attitude
- ensure good communication and information
- ensure good physical accessibility
- adopt a good procedure
- ensure support is available
- have resources available
- create meaningful involvement
- consider all practical issues – before, during and after involvement.

1.3 Monitoring and Review

The principles and standards underpinning this policy will be audited regularly to inform continuing improvement and development of CSIP as an organisation, and the development of our staff. These principles and standards will be incorporated within CSIP’s performance review.
Chapter 2- Scope

2.1 Strategy and Governance

Service users and carers will be involved in the decision making specific to CSIP’s strategic direction, delivery of programmes, and deployment of resources.

When CSIP is planning its work and allocating budgets the views of service users and carers, and allied organisations reflecting those views will be considered.

Identification, selection of and support for people to be involved will be transparent and promote equal opportunities.

CSIP and each Regional Development Centre will:

- work with and through service user and carer networks
- support people at each stage of engagement
- develop links with the wider community
- ensure involvement is evident and that it influences decision making

2.2 Work Programmes

Work stream and programme leads are responsible for ensuring that appropriate processes are in place to enable people to participate.

It is the responsibility of work stream and programme leads to ensure that service users and carers have informed the development of proposals and work plans.

2.3 Procedure for Involving Service Users and Carers

When a service user or carer enquires about, or is approached about involvement opportunities, CSIP shall:

1. Make initial contact and give an overview of involvement opportunities
2. Send an information pack for people to consider the implications of becoming involved
3. Follow a fair and transparent selection procedure for specific involvement opportunities
4. Meet with service users and carers selected
5. Make specific practical arrangements
6. Ensure service users and carers have the same level of information as other stakeholders and are supported in digesting it.
Information Pack

This will include:

- a covering letter
- introduction to CSIP and details of involvement opportunities
- information about entitlements including training and development opportunities, payments, expenses, mentoring and support
- CSIP’S policy for involving service users and carers and other relevant policies
- any registration forms & involvement agreements used by the Regional Development Centre

Involvement Opportunities

People may wish to be involved at different levels, and to different degrees, within CSIP. Some people may wish to attend events in an informal manner where the principles of good practice should be followed.

For specific involvement opportunities people should be given the following information:

- the purpose of involvement
- the breadth of decision making on offer and the extent of authority and influence that participation is expected to deliver
- the process of selection
- knowledge, skills and experience applicable
- entitlements
- time commitment
- training and support provided
- how support needs can be put in place (where needed).

Payments

All payments will be made in accordance with the CSIP payment policy

Registration Form

Service users and carers who express an interest in being involved in the work of CSIP will be asked to fill in a registration form. This will record the personal details of the person in question and identify where they may feel they would like to make a contribution within CSIP work. This information shall be held securely within the relevant RDC information database.

Information sharing

Arrangements for supporting individuals may need to involve other staff within CSIP (for example, administrators, events co-ordinators and business managers). In all cases sensitivity and discretion are essential and personal information should be shared only with the expressed permission of the participant.
Criminal Record Bureau – Disclosure of Information

The Criminal Records Bureau (CRB) has been established to provide organisations with the means to check the background of job applicants or volunteers to ensure they do not have a history that would make them unsuitable for the job applied for.

CSIP will not apply for disclosure on every service users and carer who gets involved. However, in some circumstances, it may be appropriate for CSIP, in conjunction with their host organisation, to seek disclosure; for example, if the proposed involvement activity is to happen in a clinical setting.

If a ‘disclosure’ is required, this will be stated at the time the involvement opportunity is advertised and the process will be explained. An “Application for Disclosure” will only be made for those invited to be involved.

Specific Practical Arrangement to Support Children and Young People

The safety of children and young people is paramount and CSIP will ensure that any involvement follows the guidelines set out in ‘The Children’s Act 2004’ and ‘Working Together to Safeguard Children’ (HM Government 2006)

The principles set out in the CSIP ‘Standards of Good Practice’ document accompanying this policy apply equally to children and complement those set out in ‘Hear By Right’ (NYA 2005) and ‘Learning to Listen’ (Children and Young Peoples Unit 2004) but particular attention needs to be paid to:

- providing accessible information ahead of the event
- coaching the children and young people to enable them to listen effectively, present their views constructively and to research information for themselves.
- ensuring an agreed understanding of confidentiality
- recognition of their input by providing credit in documents or formal accreditation via a recognised youth achievement scheme.
- practical matters such as transport, venues that are not intimidating, whether or not adult support is needed and events that are enjoyable.

2.4 Communications

Each project, work stream and programme shall have a communications plan in line with the CSIP Communications Strategy.

Staff will seek the views of service users and carers about communication and how effective this communication is.

Communications plans will address how different and diverse groups and individuals will be contacted and which media will be used.

It is the responsibility of the work stream and programme leads to ensure that dissemination information is accurate and covers relevant networks and groups.

Communications shall be monitored and evaluated routinely both regionally and nationally.
Where it has been identified as a development need, CSIP staff will be offered opportunities to develop their communications skills.

2.5 Recruitment of Staff

Where CSIP posts become vacant, and where new posts become available, CSIP will ensure that:

- service users and carers contribute to the design of job descriptions and person specifications;
- vacancies are routinely advertised through service user and carer networks.
- service users and carers play an active role in short listing and selection processes.

2.6 Monitoring and Evaluation

Feedback from participants will be reported within the work stream or programme’s performance monitoring system.

The involvement of service users and carers will be monitored through national and regional performance and governance arrangements.

2.7 Staff Development

Induction

All new recruits will receive information and training on involving service users and carers as part of their induction.

Ongoing Training

All CSIP staff will be expected to attend a training course and subsequent updates on service user and carer participation. This will assess their knowledge, skills and understanding around involving people within their work programmes.

Supervision and Appraisal

Service user and carer participation will be a key dimension of performance which CSIP staff and associates will consider with their line managers in supervision and appraisal. Where continuing development is identified as a need this will be negotiated and agreed as a priority.
Issues, Concerns or Complaints

Where any issues of concern arise, these should be reported immediately to the relevant line manager. Should a complaint ensue, the person making the complaint should be helped to access the relevant “Complaints Policy and Procedure”.

Regional directors and senior management teams will review any complaints, incidents or issues which emerge from the participation of service users and carers.

Chapter 3 – Review of this Policy

A review of this policy will be undertaken one year from its implementation.

Responsibility for the review will be held by the NIMHE management board.
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Carer</td>
<td>Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.</td>
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<tr>
<td>Care Services Improvement Partnership (CSIP)</td>
<td>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.</td>
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<tr>
<td>Experts by Experience (EbE)</td>
<td>A national service user and carer group which was part of NIMHE.</td>
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<td>Local Implementation Team (LIT)</td>
<td>An organisation made up of stakeholders from different organisations including service users, carers and health and social services staff. Responsible for agreeing the direction for mental health services locally and for implementing national mental health policy.</td>
</tr>
<tr>
<td>National Institute for Mental Health England (NIMHE)</td>
<td>Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.</td>
</tr>
<tr>
<td>PCT (Primary Care Trust)</td>
<td>Organisations which are based in primary care and responsible for commissioning health services for the local population.</td>
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<tr>
<td>Programme Lead</td>
<td>A member of NIMHE staff responsible for leading a programme of NIMHE’s work either at a national or a regional level.</td>
</tr>
<tr>
<td>Regional Development Centre (RDC)</td>
<td>NIMHE has eight regional development centres.</td>
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<tr>
<td>Service user</td>
<td>Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems.</td>
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Other Terms used within this report include:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Health and Social Care Advisory Service (HASCAS)</td>
<td>An advisory service working in all aspects of mental health and older peoples services – HASCAS wrote the Making a Real Difference Report</td>
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<tr>
<td>Directors</td>
<td>The senior managers in each CSIP Development Centre</td>
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<tr>
<td>Products</td>
<td>The policies, procedures, guidelines and systems developed during the Making a Real Difference project.</td>
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<tr>
<td>PRINCE2</td>
<td>Projects IN Controlled Environments, a structured way of managing projects.</td>
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<td>Work Group</td>
<td>One of the seven groups that were tasked with developing the Making a Real Difference products.</td>
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<tr>
<td>Project Governance</td>
<td>A term to describe how the whole project was monitored and managed.</td>
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<tr>
<td>Terms of Reference</td>
<td>A description or the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.</td>
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<tr>
<td>Work Stream</td>
<td>Work that fits into a specific area and is often a local initiative.</td>
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<tr>
<td>Work programme</td>
<td>A nationally agreed area of work; for example ‘Mental Health’, ‘Learning Disability’. There is a local lead for each area.</td>
</tr>
<tr>
<td>Leads</td>
<td>Those who are leading on the work stream or work programme</td>
</tr>
<tr>
<td>People</td>
<td>All who have a stake in services; the wider community, staff, Service Users and Carers.</td>
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