



# Valuing Involvement

## Strengthening Service User and Carer Involvement in NIMHE

### Policy and vision statement on the purpose of involvement

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 and vision statement is designed to address some of the recommendations made within the report. It provides the principles and values which will enable NIMHE to work in partnership with people who have experience of mental health problems and their friends and families who care for them.**

### **Who is the Policy and Vision Statement for ?;**

#### **New NIMHE Staff and Volunteers**

- All new staff should familiarise themselves with the policy and vision statement to ensure that they are fully aware of the responsibilities they have, to involve people when planning, developing and delivering their work programmes. Any queries should be discussed with their line manager.
- All new work programmes should be designed in line with the policy and vision statement.

#### **Existing NIMHE Staff and Volunteers**

- Existing staff members should familiarise themselves with the policy and vision statement.
- Existing staff should ensure that their work is inclusive of the principles outlined in the policy and vision statement. If necessary a plan should be developed to outline how current work plans will fulfil the commitments made by NIMHE in this policy and vision statement
- Any new work programmes should be developed in line with the policy and vision statement.

#### **People sharing their expertise to inform NIMHE's work**

- All people should be made aware of the commitment made by NIMHE and its staff within the policy and vision statement. This will ensure that everyone is 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 commitments made in the policy and vision statement.
- All NIMHE work programmes should provide regular feedback with regard to performance against the policy and vision statement.
- All monitoring and evaluation of work programmes should include measures of performance against the policy and vision statement.

## Acknowledgements

The Policy and Vision Statement on Involvement was developed and written by Yvonne Pearson on behalf of the Making a Real Difference Project.

The work was informed and overseen by the East Midlands Making a Real Difference Work Group 1 Steering Group -

John Howatt	Karen Colligan
Piers Allott	David Gardner
Sylvia Minshull	Trish Crowson
Moira Kerr	Philip Douglas.

The make up of the steering group was as follows;

Designation	Numbers	% of group
Advisory group	8	100%
CSIP Staff	3	37.5%
People with experience of using mental health services	3	37.5%
People with experience of caring	2	25%

There are so many people across the East Midlands who influenced, supported, assisted and directed the development of this policy and heartfelt thanks go to each of them for finding the time to become involved.

Particular thanks goes to the following people for their detailed comments on the first draft:

Rob Hanlon	Graham Saxton (Derbyshire Mental Health Services Trust)
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Janet Rice	Liam Gilfellow (Project Manager Making a Real Difference)
Jean Ambrose	
Jean Bailey (Alzheimer's Society)	
Emma Eacock (RETHINK)	

**Around 430 people had the opportunity to become involved in the development of the policy and vision statement.** (The full list is attached as appendix 1)

This work is dedicated to the memory of John Howatt, a person who touched and inspired many during his long career in mental health. John was a charismatic leader, empowering in his approach and always a joy to work with.

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## **Introduction and Background to this Policy and Vision Statement**

The Care Services Improvement Partnership (CSIP) was created in April 2005 to work with children and families, adults and older people including those with mental health problems, learning and/or physical disabilities and people in the criminal justice system.

CSIP aims to work with health, local government, public, voluntary and private sectors to improve services and the health and well being of people in England.

The National Institute for Mental Health for England (NIMHE) is the mental health programme within the CSIP.

At the start NIMHE made a clear commitment to put “service users, families and communities” at the centre of its work.

In 2004 the Health and Social Care Advisory Service (HASCAS) was asked to review service user and carer involvement in NIMHE and make recommendations about how involvement could be strengthened.

The Report ‘Making a Real Difference’ (April 2005) made twenty recommendations for strengthening service user and carer involvement in NIMHE.

The first of these recommendations said that NIMHE needed to be clear about the purpose of service user and carer involvement and proposed the development of a corporate vision statement and policy which clearly outlined the purpose of involvement and confirmed the organisational commitment to involving service users and carers as partners in decision making.

This policy has been led by the East Midlands Regional Development Centre and developed in partnership with people with lived experience of managing or overcoming mental health problems, their partners, friends and family who support them and workers in the voluntary, statutory and independent sector across health and social care.

This policy sets out:

1. A corporate vision statement on the purpose of involvement.
2. The principles underpinning this statement and how NIMHE is committed to making them a reality in its everyday working practices.
3. The relevance and value of this vision statement for people who have or have had mental health problems, their family and friends, commissioners and providers of services and the wider community.

## Chapter 1 – 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.

## Chapter 2 - Putting Principles into Practice

Our vision statement is underpinned by six key principles which NIMHE is committed to putting into practice:

Principle one: Empowering and supporting people to manage their own mental health.

We recognise that people who are living with mental health problems are in the best position to know how to manage their mental health problems and achieve mental well being and we believe that they, and the people who support them, should be empowered and supported in doing so.

We believe that people who have or have had mental health problems and their family and friends have the right to the respect, information, support and resources to meet the challenges they experience.

### **NIMHE will put this principle into practice by:**

Working in partnership to create mental health services that empower and support individuals to actively manage or improve their own mental well being by ensuring that they and their family and friends have the respect, information, support and resources to enable them to do so.

Principle two: Creating services that promote hope and optimism and support people to achieve mental well being

People want mental health services that enable them, and the people who support them, to tackle mental health problems with optimism and hope, and to work towards achieving mental well being as part of a valued lifestyle within and beyond the limits of any mental health problem.

### **NIMHE will put this principle into practice by working to:**

Create services that aim to support people to either re-establish a sense of well being or achieve a good quality of life.

**Principle three:** Engaging people with direct experience in the design, development, delivery and monitoring of services

We see people who live with a diagnosis of mental illness or mental disorder and the people who support them as key consultants in the design, delivery and monitoring of mental health services.

**NIMHE will put this principle into practice by working to:**

Empower individuals with direct or indirect experience of living with or overcoming mental health problems to become actively engaged or have control of the planning, development, delivery and monitoring of services.

**Principle four:** Changing the balance of power

We accept that different people have different amounts of power in the mental health system, and that professionals, as a result of their training, their status as paid workers and their control of public resources, are placed in a more powerful position than the people receiving those services either directly, or through caring for another.

**NIMHE will put this principle into practice by working to:**

Address the differences in the amount of power that people have by supporting professionals to recognise where these differences exist and seek to reduce them in partnership with the people using services and their family and friends, by challenging bad practice and working to shift power through information, funding and decision making.

**Principle five:** Respecting diversity

We will respect diversity by working in partnership to provide care and interventions that not only make a positive difference but also do so in a way that values and respects diversity including age, race, culture, impairment, gender, spirituality and sexuality.

**NIMHE will put this principle into practice by:**

Developing ways of achieving genuine participation and equality of involvement from black and minority ethnic communities and diverse and marginalised communities.

Principle six: Challenging inequalities and promoting active community engagement

We will work to address the causes and consequences of stigma, discrimination, social inequality and the exclusion of people living with and overcoming mental health problems.

We will promote social inclusion and active citizenship to create an environment where people are treated as equal and valued members of the communities where they live, work and socialise.

**NIMHE will put this principle into practice by working to:**

Tackle the stigma and combat the severe prejudice and discrimination surrounding people with mental health problems and their families with regard to employment, access to health care and the judicial system.

We will work in partnership with a wide range of agencies beyond health and social care to promote active engagement with local communities.

## **Chapter 3 - The Relevance and Value of this Vision Statement**

This section describes the key elements of the vision statement and outlines their relevance and value for the individual, their family and friends, commissioners and providers of services and the wider community.

### **3.1 Value to Individuals**

This vision statement explicitly links involvement with empowerment. All involvement activity should be individually empowering and encourage autonomy, responsibility and self management. An approach based on empowering people to take control represents a challenge to traditional ways of working where mental health professionals have tended to exercise control over treatment decisions, information, resources and decision making. Involvement which encourages people to be in control emphasises their strengths rather than their deficits and is known to have a positive effect on their mental health.

Services should be clear about what outcomes they are hoping to achieve. The statement suggests that services should aim to support people in achieving a level of mental health and well being which is satisfactory to them. Services that promote mental well being encourage hope and optimism which provides the best environment for an individual to achieve a quality of life that is satisfactory to them.

### **3.2 Value to Service Commissioners and Providers**

People with lived experience of using services, overcoming their mental health problems without services, or supporting a family member or friend bring expert knowledge which is crucial for service development, delivery, monitoring and evaluation. They can offer informed comment on what works and what doesn't, how services should be organised and delivered and what outcomes are relevant to support people in achieving the outcomes they want. This is the added value they bring to any partnership.

People who are 'experts through their lived experience' have often developed a range of coping mechanisms, survival strategies and recovery techniques to manage their mental health problems. Service providers, other people with mental health problems and their family and friends need this shared expertise. If people are enabled and supported in self management it may decrease the need for them to rely on formal services and professional supports.

### **3.3 Value to communities**

A key purpose of involvement is to challenge barriers to active engagement in local communities caused by stigma, discrimination, prejudice, lack of access to employment and health services.

# Glossary

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

Carer	Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.
Care Services Improvement Partnership (CSIP)	An organization formed in April 2005 to bring together NIMHE with other Department of Health Groups which cover people with learning disabilities, older people and children and young people.
Experts by Experience (EbE)	A national service user and carer group which was part of NIMHE.
Local Implementation Team (LIT)	An organisation made up of stakeholders from different organisations including service users, carers, health and social services staff. Responsible for agreeing the direction for mental health services locally and for implementing national mental health policy.
National Institute for Mental Health England (NIMHE)	Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.
PCT (Primary Care Trust)	Organisations which are based in primary care and responsible for commissioning health services for the local population.
Programme Lead	A member of NIMHE staff responsible for leading a programme of NIMHE's work either at a national or a regional level.
Regional Development Centre (RDC)	NIMHE has eight regional development centres.
Service user	Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems

Other Terms used within this report include;

HASCAS – Health and Social Care Advisory Service	An advisory service working in all aspects of mental health and older peoples services – HASCAS wrote the Making a Real Difference Report
Directors	The senior managers in each CSIP Development Centre
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.
PRINCE2	PRojects IN Controlled Environments, a structured way of managing projects.
Work Group	One of the seven groups that were tasked with developing the Making a Real Difference products.
Project Governance	A term to describe how the whole project was monitored and managed.
Terms of Reference	A description or the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.

RATIFYING BODY .....
DATE RATIFIED .....
NEXT REVIEW DATE .....
TO BE APPROVED BY .....

## Appendix 1 - Acknowledgements

### Individual interviews:

Individual interviews about both the purpose of involvement and good practices in communication were undertaken with:

- 10 East Midlands CSIP programme leads,
- 2 communications managers of national voluntary organisations,
- 1 national voluntary sector head of user and carer involvement, along with their regional involvement worker.
- 1 local authority manager of user and carer involvement,
- 2 mental health trust leads for user and carer involvement.
- 1 policy lead responsible for developing the involvement strategy for a city community partnership
- 2 long standing service user activists
- 4 managers of local Black and Minority Ethnic (BME) agencies

### Meetings, forums, networks and events

The purpose of involving people and how communication can strengthen involvement were discussed at the following events, forums and meetings:

- East Midlands Carer Support Worker Network on 9<sup>th</sup> May 2006 attended by 32 mostly voluntary sector carer support workers covering the East Midlands area.
- East Midlands Mental Health Network event for people with direct or indirect lived experience of mental health held in Northamptonshire on 23<sup>rd</sup> May 2006 with around 80 service users and carers
- Nottinghamshire Carer Link workers on 24<sup>th</sup> May 2006, around 10 workers across a range of mental health settings.
- Carers Council Nottinghamshire open evening on 7<sup>th</sup> June with around 10 carers.
- Carers Group in Nottingham on evening of 12<sup>th</sup> June at an outer city estate arranged by RETHINK with 6 carers
- Evening meeting with 4 young carers from 11 to 15 years in Derby on 3<sup>rd</sup> July arranged by Derbyshire NCH Young Carers Project
- Focus group of 2 carers and 7 service users from Lincolnshire, Nottinghamshire, Northamptonshire held in Sleaford on 4<sup>th</sup> July arranged through CSIP
- Focus group of 4 African Caribbean service users in Nottingham Tuesday 11<sup>th</sup> July arranged by Amaani Tallawah Nottingham on
- Meeting with 9 older people with dementia and their carers at Alzheimer's Café on 20<sup>th</sup> July 2006 in Ripley, Derbyshire arranged by the Alzheimers Society.
- Meeting with group of 10 people with early onset dementia and their carers in Derbyshire on 27<sup>th</sup> July 2006 to look at purpose of involvement and involvement toolkit arranged by Alzheimer's Society

- Meeting in Leicester at African Caribbean Centre with approx 60 African, African-Caribbean and Asian carers and service users organised by Akwaaba Ayeh, the East Midlands Carer Development worker for Afiya Trust, SAVA and LAMP.
- Nottingham City BME women and mental health group - 11<sup>th</sup> August 2006 organised by Nottingham City Community Mental Health Team (CMHT) with 7 BME service users.
- Younger people with dementia and their carers across Derbyshire organised through Alzheimer's Society on 14<sup>th</sup> September 2006 attended by 14 people with dementia and their partners.
- Rural carers from Rutland and Leicestershire organised through Leicestershire RETHINK on 15<sup>th</sup> September 2006 with 10 carers
- Members of the Alzheimer's Café in Ripley, Derbyshire 18<sup>th</sup> September 2006 with 17 people with dementia and their carers from a rural setting.
- East Midlands Mental Health Network event for people with direct or indirect lived experience of mental health in Sleaford Lincolnshire on 4<sup>th</sup> October 2006 – around 50 service users and carers.

In mid October a substantive draft of the involvement statement was circulated by post and email to around 70 service users, carers and workers in both the statutory and voluntary sector who had been actively involved in its development.

After redrafting, the policy and statement was discussed further at:

- Derbyshire/Derby City Carers Strategy Group on 17<sup>th</sup> October 2006 which included 8 carers, PCT commissioning lead, Derbyshire Care Programme Approach (CPA) Coordinator, Service Manager Derbyshire Mental Health Trust, Local Authority Carer Lead and voluntary sector provider agencies
- Nottingham City African Caribbean Carers Group on 19<sup>th</sup> October 2006 attended by 7 African Caribbean Carers and supported by the City Community Mental Health Team.
- Members of the Alzheimer's Café in Ripley, Derbyshire on 19<sup>th</sup> October with 14 people with dementia and their carers from a rural setting.
- Leicestershire and Rutland carers group on 20<sup>th</sup> October organised by RETHINK with 10 carers from a rural area.
- North Derbyshire Carers Forum on 25<sup>th</sup> October 2006 attended by 25 carers
- Younger people with dementia and their carers across Derbyshire organized through Alzheimer's Society on 30<sup>th</sup> October 2006 – 10 people with dementia and their partners attended.
- Amber Valley Carers Group supporting older people with dementia organised by Amber Valley CMHT on 1<sup>st</sup> November with 11 carers of older people.

The first draft was submitted to the national Making a Real Difference steering group on 3<sup>rd</sup> November 2006 and following minor amendments was resubmitted to the steering group on the 7<sup>th</sup> September for sign off.

### **Summary of involvement activity.**

The East Midlands adopted a policy of trying to attend existing community groups, forums and meetings rather than expecting people to travel to a new event. This policy worked well in reaching BME communities. In terms of 'out of reach' communities a great deal of effort was made in the planning of the major "Regional Mental Health Network" events to attract local users and carers who were not part of any local groups.

A small social meeting was arranged specifically for the project on only two occasions in order to meet with young carers and African Caribbean service users.

### **Around 430 people had the opportunity to become involved in the development of the policy and vision statement on the purpose of involvement and/or the communication strategy.**

- In all, around 360 people with a direct or indirect experience of managing mental health problems were involved across the East Midlands. Interestingly, of this group of 360 people, almost half were service users and the other half carers. Despite the fact that more of the community meetings were with carers, a high proportion of service users attended each of the main East Midlands Network events.
- Around 70 workers were also informed and consulted about the two policies.

**Of the 430 people who were involved some 22% (around 100) were from BME communities**