



*National Institute for
Mental Health in England*

Making a Real Difference

*Strengthening Service User and Carer
Involvement in NIMHE*

Final report

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HASCAS
Health and Social Care Advisory Service

Acknowledgements

The energy, passion and commitment of those who are striving to create effective service user and carer involvement in NIMHE is impressive.

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Executive Summary

The National Institute for Mental Health England (NIMHE) is part of the Department of Health and was established in 2002. NIMHE has a small, central team based in Leeds which includes individuals leading on national programmes of work. NIMHE also has eight regional development centres (RDCs) each of which is hosted by an NHS organisation.

NIMHE set out to put people who use mental health services at the centre of everything it does. During the past two years significant efforts have been made to involve service users and carers within NIMHE programmes, within NIMHE centrally and within the regional development centres. This project, carried out by a team predominantly made up of service users and carers, from HASCAS:

- Looked at how well NIMHE is doing this, and what else needs to happen for service user and carer involvement to be strengthened.
- It involved listening to service users and carers (including people who do not necessarily identify themselves as service users or carers), and staff from NIMHE and from the Department of Health. It has also looked at previous work to discover what makes service user and carer involvement work.
- Developed a framework for NIMHE to strengthen service user and carer involvement for the future. This formed the basis of a consultation document which was widely circulated and has been further developed in the light of the comments received.

THE MAIN FINDINGS

The findings from the review of what is currently happening are:

- NIMHE is a relatively young organisation, which is developing a range of ways that service users and carers can become involved.
- There are good examples both at a national and a regional level of service user and carer involvement in NIMHE.
- While it is true to say that some service users and carers are able to express their views and influence NIMHE, this is not the case for all. In particular the involvement of the following groups of people tends to be poor: black and minority ethnic communities, older people, younger people, gay, lesbians and bisexuals, people living in rural communities, people using primary care mental health services, people with a diagnosis of personality disorder, prisoners and those in secure services.
- It is clear that service users are better involved than carers.

- The overall assessment of service user and carer involvement suggests that they feel they have little influence over NIMHE, neither on setting the agenda nor in making decisions. The majority of people would like to see this situation changed for the better.
- At a national level service users and carers can be, and are involved in national programmes including research. However, while there is a national service user and carers group - the Experts by Experience group - its purpose is unclear and it is not well resourced. Nor does it have a formal link to decision-making (executive) bodies.
- There was a more positive evaluation of involvement at a regional level in the eight development centres, and there is significant investment in support of it. Despite this, issues remain about the role of the service user and carer leads, their position within the development centres, their responsibilities and the variations in their levels of remuneration.
- It must be recognised that NIMHE will need to operate differently if it is going to involve a greater degree of diversity amongst service users and carers. This will involve going out to where people are, developing different ways of working and addressing the barriers which currently restrict involvement, including tackling different forms of discrimination.
- It is clear that service users and carers and staff working for NIMHE want to see involvement strengthened.
- The first step to strengthening involvement is ensuring that there is the organisational commitment to do so; this means a clear commitment to involve service users and carers in setting the agenda and in decision-making.
- For NIMHE to strengthen service user and carer involvement it needs to be clear about the purpose of being involved, provide more information, pay particular attention to strengthening diversity and develop representative structures.
- NIMHE also needs to ensure that there are clear processes for recruitment, induction and training and practical support available to facilitate involvement.

FRAMEWORK FOR INVOLVEMENT

The proposed framework builds on the findings from the project and has been developed through the Reference Group. There are four levels to this framework as follows:

1. A clear purpose for the involvement of service users in NIMHE

The purpose of involvement needs to be clearly stated so that service users and carers know what they are getting involved in and why. If the approach outlined in NIMHE's strategy is to be achieved then the purpose of involvement should be to increase the influence of service users and carers in defining NIMHE's work programme, in improving and developing services and to build capacity to support involvement beyond NIMHE. This purpose needs to be supported by principles, values, a social model of disability and a process of involvement which aims to build capacity.

2. A positive organisational culture

NIMHE needs to ensure that there is an organisational culture within which involvement can flourish. Measures to develop this culture include service user- and carer-focused leadership, involvement in governance arrangements, staff development, employment of service users and carers, setting out to secure diversity, resources to make it happen and regularly monitoring and reviewing the impact of what has been put in place.

3. Provision of support to get involved

The approach NIMHE takes to involvement needs to be flexible and seek to engage with a diverse range of people in the places where they meet. Practical and emotional support needs to be available, as necessary, to facilitate involvement. This includes clear accessible information in a variety of formats, prompt payment of expenses and fees, administrative support, capacity building and training.

4. Structures for empowerment and representation

Involvement needs to start with investment in local groups and there needs to be a mechanism for connecting this activity to the regional development centres and at a national level so that this local agenda can influence the work that NIMHE does on its behalf. The development of independent service user and carer forums at a national level and a representative structure has the potential to facilitate this. The existence of a national programme whose aim is to support the regional development centres in their role of strengthening local involvement would provide an effective means of coordinating effort and resources.

RECOMMENDATIONS

1. NIMHE needs to be clear about the purpose of service user and carer involvement and decide whether or not to involve service users and carers as partners in decision-making and to develop areas of work where service users and carers lead and have overall control.
2. NIMHE needs to have a broad range of ways of engaging with people experiencing mental distress, their families and carers, including going to where people meet, informal events and focused approaches to ascertaining service user and carer views.
3. A key focus of NIMHE's work on involvement should be enabling and supporting service users and carers to be involved in local groups. The investment in and development of a national user group and a national carer group, with appropriate and clear relationships to regional development centres and to local groups will enable the local agenda to be reflected at a national level.
4. NIMHE should establish a programme for service user and carer involvement with a national lead at Director level. The role would be to facilitate work across NIMHE on the key issues identified, to coordinate the work of regional development centres and work with external organisations to develop a coherent approach to involvement.
5. The involvement of service users and carers across all NIMHE programmes needs to be strengthened. All programmes need to consider how to involve service users and carers at the start and all the way through the process.
6. NIMHE needs to strengthen its approach in relation to involving diverse groups. All programmes and development centres should identify how they are going to broaden the diversity of those involved..
7. Service user carer and support should be underpinned by robust support at all levels, which pays attention to support and development needs arising from a transition in role as a result of a different type of involvement or involvement at a different level.
8. NIMHE needs to develop an effective communications strategy which is accessible to a diverse range of service users and carers.
9. NIMHE should review arrangements with the host organisations to have a standardised approach to ensure that their policies and procedures support the development of service user and carer involvement in NIMHE.
10. NIMHE needs to develop a single payment policy across all the RDCs and programmes. This should be negotiated with the Department of Work and Pensions.

11. NIMHE needs to review the differential payment of staff in service user and carer lead roles across and within RDCs. The position of both paid staff and those who are paid for their involvement needs to be reviewed in the light of current employment legislation.
12. NIMHE needs to consider how it is going to strengthen the organisational climate to support involvement.
13. NIMHE needs to develop a way of monitoring involvement which involves service users and carers.
14. NIMHE needs to work with PCTs to support investment in the development of local service user and carer groups in order to develop local groups which can then be involved in other local, regional and national forums including NIMHE.
15. A clear and costed implementation plan needs to be developed to progress the actions identified. This needs to include the transition from the current arrangements to any new arrangements.
16. NIMHE needs to safeguard the current level of involvement during the establishment of CSIP and work with CSIP to ensure that service user and carer involvement is built into the new organisation and that the proposals outlined in this report are implemented.

Chapter 1 Setting the Scene

1.1 Background

The National Institute for Mental Health England (NIMHE) is part of the Department of Health and was established in 2002. NIMHE has a small central team of staff based in Leeds which includes individuals leading on national programmes of work, for example workforce development, acute in-patient care and race equality. NIMHE also has eight regional development centres (RDCs) each of which is hosted by an NHS organisation as detailed below.

Regional Development Centre	Host Organisation
London Development Centre for Mental Health	Camden and Islington Mental Health Trust
NIMHE Eastern	North Essex Mental Health Trust
NIMHE East Midlands Development Centre	Lincolnshire Partnership Trust
NIMHE North East, Yorkshire and Humber	Bradford District Care Trust
NIMHE North West	Cheshire and Merseyside Strategic Health Authority and Pennine Care Trust
NIMHE West Midlands	West Midlands South Strategic Health Authority
South East Development Centre	Isle of Wight and Hampshire Strategic Health Authority
South West Development Centre	Dorset and Somerset Strategic Health Authority

Box 1: NIMHE regional development centres and their host arrangements

NIMHE¹'s (NIMHE, 2003) stated mission is:

"To improve the quality of life of people of all ages who experience mental distress. Working beyond the NHS, we help all those involved in the NHS to implement change, provide a gateway to learning and development, offering new opportunities to share experiences and one place to find information. Through NIMHE's development centres and programmes of work, we will support staff to put policy into practice and offer help to resolve local challenges in developing mental health".

¹ Recovery and Change – Mental health into the mainstream: Annual Report and Strategic Plan 2002/03-2005/06

At the start NIMHE made a clear commitment *“to put people who use services at the centre of everything we do”* and *“involve service users and carers in the planning and delivery of work drawing on those service user experiences and existing good practice”*². It made it clear that in order to achieve the aims above, *“service users, families and communities will be at the heart of our work”*³. During the past two years real efforts have been made to involve service users and carers within NIMHE programmes, within NIMHE centrally and within the regional development centres.

However the commitment made by NIMHE sets a high standard for it to achieve meaningful involvement of service users and carers in its ambitious programme of activities. Further, as a new organisation, with a far-reaching agenda involving many players, the processes of service user and carer involvement have evolved differently within different programmes and in the eight regional development centres.

The NIMHE Executive Team decided that it was therefore timely to review service user and carer involvement at all levels throughout NIMHE. The purpose of this was to develop a more coordinated and strategic approach which aims to strengthen service user and carer involvement and move closer to NIMHE's stated commitment.

The project has been managed by North East, Yorkshire and Humber NIMHE on behalf of NIMHE and the other regional development centres. The work has been undertaken for NIMHE by the Health and Social Care Advisory Service (HASCAS).

1.2 This report

This report provides an overview of the aims of the project, the way in which it was undertaken, the key findings and a way forward. It includes quotes taken directly from what different people have said, including service users, carers and NIMHE staff, and reflects some of the different perspectives. In order to protect confidentiality the source of these quotes has not been identified. This report is fairly lengthy; in order to make it more accessible there is a summary of the key points at the end of each chapter.

- Chapter 1 provides the background to this work, the aims of the project and how it was undertaken
- Chapter 2 draws out the key messages from what has been written about service user and carer involvement
- Chapter 3 provides the key findings of the review and includes an overall assessment of NIMHE's progress in involving service users and carers

² First strategy for NIMHE

³ Recovery and Change as above

- Chapter 4 builds on this to develop a framework for strengthening service user and carer involvement in NIMHE. The responses to a process of consultation, outlined below in 1.4, have directly informed the reworking of the framework
- Chapter 5 reflects on the future, particularly on how this work might be taken forward as NIMHE moves into the proposed Care Services Improvement Partnership (CSIP)
- Chapter 6 concludes with recommendations for NIMHE (and CSIP) on taking this work forward

Terms used

The terms 'service user' and 'carer' have been used throughout the report to describe people who have or are experiencing mental health issues and people who care for someone with a mental health problem. They are shorthand, reflect the terminology used by NIMHE and should not deflect from seeing service users and carers as people first.

The term service user is used broadly to cover:

- Anyone who has experienced mental distress, may or may not access mental health services and chooses to define themselves as a service user
- People with previous experiences of distress and/or services and consider themselves 'recovered', but who still identify with the issues experienced by those with mental distress. These people may call themselves ex-users

The term carer is used to cover family members, friends or neighbours who are providing regular support to someone experiencing mental distress.

We realise that these terms are contentious and that some people prefer other terms for example, 'survivor', 'consumer' or a person with 'lived experience' and 'family carer' or 'relative/friend'. It is also important to recognise that some people may be both a service user and a carer. We are also aware that the terms reflect which services people might be using and it was suggested to us, on more than one occasion, that 'patient' was a more accurate way of describing primary care service users.

1.3 This project

Project Aims

The project has had four aims:

- To establish what is currently happening and review service user and carer involvement at both a regional and national level.
- To identify how the involvement of service users and carers can be strengthened and mainstreamed at all levels within NIMHE, specifically the:
 - o Delivery of national work programmes
 - o Regional development centres (RDCs)
 - o Executive functions of NIMHE
- To develop and consult on a framework for the involvement of service users and carers at both national and regional levels.
- To make recommendations for strengthening user and carer involvement within NIMHE.

Method

In order to meet these aims different methods were used. In particular the project made extensive efforts to get views from a broad range of stakeholders including service users and carers with no history of involvement with NIMHE, those with experience of involvement and those who do not identify themselves as service users and carers.

In summary, the process has involved:

1. Scanning the available literature to identify key issues, broad principles and good practice for involving service users and carers in mental health services and more broadly with attention to the diversity of service users and carers.
2. Reviewing information received from NIMHE on strategy in relation to service user and carer involvement. This included annual reports and terms of reference for key groups.
3. Collecting basic information from the regional development centres to establish what service users and carers are currently involved in and what investment is being made by the RDCs. Collection of this information has proved difficult and in some instances had to be estimated. It has therefore been interpreted cautiously.
4. Focused interviews with different stakeholders, both internal and external to NIMHE as follows (with numbers indicated in brackets):

- Senior managers within NIMHE: the Chief Executive, regional development centre Directors and national programme leads (8)
- NIMHE Fellows and Champions and members of the Experts by Experience Group (7)
- Service user and carer development leads in regional development centres (15)
- Programme leads in regional development centres (9)
- Service users and/or carers in lead roles on regional groups (5)
- Senior Managers from the Department of Health (5)

The aim of these interviews was to identify how well the current arrangements are working, what is difficult, how the current arrangements could be strengthened and the priorities for development.

A brief questionnaire was sent to a sample of programme leads within the development centres to similarly identify how well current arrangements are working. The response rate to this was 20%.

5. Focus groups with service users and carers which were designed to listen to the views of service users and carers and to explore the key issues which had been raised either during the initial interviews or from the literature. Particular attention was paid to recruiting service users and carers who may not typically be involved in NIMHE and those who might not primarily identify as a service user or carer.

Approximately 500 people were involved in these focus groups, including over 230 people from black and minority ethnic communities (BME) who attended the focus group specifically targeted at these communities.

6. Attending meetings of existing networks which provided an opportunity to hear from those who are currently involved in NIMHE's work. A full list of the meetings attended and the focus groups organised is available in Appendix 2.
7. A questionnaire for service users and carers was widely distributed, via Mindlink, which has approximately 1000 service users on its mailing list and disseminated at events and through the RDC networks. 250 questionnaires were returned.
8. Invitations to national voluntary organisations to comment, including both mental health and other voluntary organisations. 13 responses were received.

Project Team

The project team was made up predominantly of service users and carers with additional input from the research team at HASCAS. Membership of the project team is available in Appendix 1. The project team has been supported by a

Reference Group which has provided additional expertise on service user and carer involvement, also listed in Appendix 1.

1.4 Consultation

A framework, which aimed to strengthen service user and carer involvement in NIMHE, was developed on the basis of the findings. Together with a draft version of this report, this was widely circulated for consultation for two months from the end of November 2004 until January 2005. 58 written responses were received with approximately half from individuals including service users and carers (52%) and half from groups or organisations (42%). A summary of the responses to the consultation are available on the NIMHE website at www.nimhe.org.uk.

Summary

- **The National Institute for Mental Health England (NIMHE) set out to put people who use mental health services at the centre of everything it does.**
- **This project has looked at how well NIMHE is doing this, and what else needs to happen for service user and carer involvement to be strengthened.**
- **The project has involved listening to service users and carers, a wider audience of people who do not necessarily identify themselves as service users or carers, staff from NIMHE and from the Department of Health. It has also involved looking at what has been found out before about what makes service user and carer involvement work.**
- **The project team that undertook this work was mainly made up of service users and carers.**
- **This report provides a summary of the project, its main findings and what needs to happen for NIMHE to strengthen service user and carer involvement for the future. It has been informed by consultation on an earlier version.**

Chapter 2 What the literature says

There is extensive literature on user and carer involvement which has been developed over the last twenty years; much of it on user involvement. At an early stage in this project some 80 academic papers, policy documents and reports describing innovative projects were considered. This did not constitute a formal literature review as this was outside the scope of the current project. Further, there has been a number of high quality reviews published recently. We would like to draw attention to two comprehensive reviews, published by the NHS Service Delivery and Organisation Research and Development (NCCSDO), by Crawford et al (2003) on the literature on user and carer involvement in organisational change and Rose et al. (2002) on user and carer involvement in change management in a mental health context. These and other reviews provide a helpful background to the current project. They enable the identification of factors which help or hinder effective service user and carer involvement in health and social care and lessons for strengthening involvement.

There are six themes in the literature which are helpful to consider in relation to this project. These are:

- The purpose of involvement
- Types of involvement
- Barriers to involvement
- Effective involvement
- Issues and factors to be avoided
- Involving diverse groups

2.1 Purpose of involvement

From the literature it is possible to identify three main reasons for involvement. These are:

- Involving service users and carers to ensure organisations address social problems confronting local communities. A central driver for user involvement in public sector health and social care in the UK emanates from central government. Within a policy framework which emphasises increased transparency and democratic accountability to local communities, service user and carer involvement is seen as a means of ensuring provider organisations are more closely embedded in their local

communities, and responsive to local needs. This is particularly important for users of public sector organisations, whose choice of service provider is invariably limited.

- Involving service users and carers as critical consumers. There is a long tradition beyond the public sector services, of organisations seeking user feedback for purposes of product development and gaining organisational benefit. This has been of particular relevance in the independent sector, in which there is close association between user satisfaction and commercial success. Beresford (2000) has described this as the 'consumerist' approach where the aim is to improve the product (in this instance mental health services) and is essentially about service user involvement meeting the needs of the organisation.
- Involvement as a means of empowering disadvantaged and excluded social groups, giving them voice and influence in systems which often exert significant influences over their lives. Beresford distinguishes this from the approach above describing it as the "democratic approach", particularly linked with organisations and movements of disabled people. He writes, "*It is mainly concerned with people having more say in agencies, organisations and institutions which impact upon them and being able to exert more control over their lives*". User involvement for this purpose is frequently described as having intrinsic benefits to individual participants. It could also be seen as having a value base which derives from principles of autonomy and self-determination.

These three distinct purposes of user involvement present particular difficulties challenges for public sector organisations. Their implementation challenges traditional modes of practice and raises contradictions in meeting multiple stakeholder agendas.

It is particularly important to note that the work of Crawford et al (2003) identified the need for explicit organisational clarity about the aims of user involvement as the most significant factor in ensuring success or failure of user involvement. Others have developed this theme to identify the need for clarity about what and what cannot be achieved through participation (Carr 2004) and the need to state at the outset what the involvement is *for* with the option of continuous negotiation and agreement (Carter and Beresford, 2000; NSF 1997 & SDC, 2001).

2.2 Types of involvement

The literature describes various forms of involvement, much of it in relation to consultation. It is advocated that there is a need for flexible methods and approaches, each carrying different levels of involvement and responsibility (IAHSP, 2003 & Carr, 2004). Further the importance of service users and carers being involved in the whole process from the very beginning of a project or activity is highlighted (Burns et al, 1994). A strong message is that involvement

which does not influence the outcome or the process that is being developed, can be characterised as an empty ritual of participation and should be avoided.

The main types of involvement identified are:

Agents in control

Peck et al (2002) developed a schema distinguishing the types and levels of service user involvement. This includes the construction of involvement as service users, and potentially carers, in overall control of any area of activity. Peck et al were unable to find any examples of service users in control of the overall planning for services although there are examples of service user control in the management of local services.

Partnership in political decision-making

As partners in organisational decision-making, service users and carers have a political voice and significant influence over organisational aims and strategy. Typically, user involvement means active participation in formal committee structures.

Consultation

As consultants, service users' and carers' main contribution is one of responding to initiatives determined by the organisation. Typically, the organisation retains the power to make decisions and service users are consulted in order to inform the decision-making process. Typical examples of consultation are focus groups, and responding to survey findings

Participants - carrying out core organisational tasks

As participants in carrying out core organisational tasks, service users and carers may contribute as paid employees, paid consultants, or volunteers. Examples of participant tasks are involvement in staff employment interviews, research and survey activities, undertaking staff training.

Box 2 provides a description of these types of involvement in practice with reference to the literature which provides examples.

Box 2: Types of involvement

As agents in control	Partners in political decision-making	Consultation	Carrying out core organisational tasks
Producing information Managing local services (Peck et al., 2002)	Membership of committees (e.g. Chamberlain 1993, Denning and Lawton, 1998) Participation in decision-making exercises (e.g. Black and Shillitoe 1997, Donnelly, 2003) and evaluation exercises (e.g. Donnelly, 2003 and Poulton, 1999) Strategic planning (IAHSP, 2003)	Providers of information (Poulton 1999) and feedback (IAHSP 2003) Responding to research/survey findings (Simpson et al, 2002.) Consulting service user and carer organisations (Took, 1999) and facilitating public meetings (Poulton, 1999)	Volunteering and informal help (e.g. Truman and Raine, 2002) Interviewing and making staff appointments (e.g. National Schizophrenia Fellowship 1999 and Poulton 1999) Staff trainers (e.g. Wood & Wilson-Barnet, 1999) and facilitators of workshops (e.g. Truman & Raine, 2002) Designers of curriculum for staff education (Barnes et al, 2000) Researchers, interviewers, facilitators of telephone discussion groups, developers of research tools and facilitators of focus groups (e.g. Berger et al, 1996, Rose, 2003) as employees (paid workers with a contract) (Simpson et al, 2002)

2.3 Barriers to involvement

The literature lists numerous factors that are reported to hinder effective user involvement. These include contradictions between conflicting political imperatives, ineffective methods and patterns of communication, and unrealistic organisational expectations.

Rose et al (2002) in writing about involvement in change management, identified that the role of the organisational culture is key in both facilitating and impeding service user and carer involvement:

“Change tends to be most successful when ‘soft’ change at the level of organisational culture occurs together with ‘hard’ changes in organisational structure, systems and services.

There is a danger that the government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off, rather than embedded as powerful organisational practices."

Rose et al. 2002

Resistance from professionals and service providers has also been identified as a particularly significant obstacle to achieving user involvement. This relates in part to an inadequate understanding of the nature and purpose of service user and carer involvement, and to a lack of confidence and inadequate evidence that involving service users and carers can tangibly improve services.

In addition there is a range of barriers which act to limit involvement generally and specifically in relation to a diversity of interests. These include:

- Language
- Physical access
- No account taken of sensory impairments
- Public transport
- Lack of information
- Inadequate preparation
- Lack of confidence
- Insufficient support

2.4 Characteristics of an effective model for involvement

The key to successful involvement which emerges from the different accounts is for it to be an integral and natural part of whole processes and for it to have been present in these from the very beginning. Rose et al (2002) have provided a useful description of the main factors identified from their literature review as summarised in Box 3.

Of note is the importance of:

Organisational intent and attitude

Clarity about the purpose of user involvement and the extent of users' ability to influence the organisational agenda is of primary importance. Other helpful factors are an organisational commitment to act on the view of service users; an understanding of the nature of mental distress; an acknowledgement and acceptance of an element of risk that is inevitably involved and an understanding that involvement for some people (and especially for young people) will wax and wane over time (McNeish et al, 2000). Rose et al (2002) identified proactive

professional managerial input combined with the existence of autonomous and independent user groups as important.

Box 3: Factors which facilitate user / carer involvement in change management

- Adequate resources present
- Facilitative organisational culture
- Good-quality organisational information strategy
- Autonomous user groups
- Professional champion present
- Staff training by users
- Training of users
- Payment and / or employment of users
- Representative structures
- Recognition and understanding of power differentials
- Acknowledgement of and sensitivity to factors pertaining to mental distress and practical measures in place to minimise them (for example advocacy)
- High-quality, meaningful and measurable involvement processes

Source: Rose et al, 2002

Organisational structures, policies and processes

Organisations need to translate this intent and attitude into straightforward and accessible ways of involving service users and carers in decision-making. This will include:

- Demonstrating how decisions are made and by whom
- Including checks and balances to ensure that service users and carers have an input into decision-making
- Showing what is fixed and what can be changed
- Having a mechanism in place to provide feedback on the outcomes of decisions made
- Having service user and carer input on the decision-making about the criteria used to make decisions

Before commencing involvement activities, adequate preparation is important. This includes deliberately seeking information about other successful involvement initiatives; ensuring staff involved in the activity are genuinely committed to service user and carer involvement; considering the degree of

representation needed for service users and carers involved; and providing adequate financial, training and support resources.

Power differentials are an inevitable consequence of both the mental health system and wider structural inequalities. They can be managed and to some extent mitigated only if they are made explicit. Training, various forms of support, advocacy and flexible structures all contribute to increasing the possibilities for more equal partnerships.

Information

Information and communication are an important factor promoting service user involvement in change in mental health services. In the mental health literature, effective information strategy is cited as facilitating involvement twice as often as are formal representative structures. The timing and quality of information are therefore key issues for effective and inclusive involvement.

There are a number of aspects to this. Firstly information about the organisation needs to be readily available, accessible, easy to understand and available in different formats/languages. Information needs to be characterised by the use of clear, understandable, concise, specific, and unambiguous information/language. Secondly there needs to be a range of ways of making contact with and engaging with people, for example diverse communities, young people, older people, people who spend long periods in their own homes and other people who are particularly marginalised. It has been suggested that ways of facilitating *active* people to enable others who are *less active* to have their say could be developed (Thornton, 2000). Thirdly sustained processes of user involvement require a two-way process of ensuring users can raise their concerns to the organisation, as well as addressing the issues an organisation wishes them to work on. Adequate means of feeding back findings and outcomes to users are needed, including the reasons for any failure to implement the changes sought.

Factors pertaining to mental distress

Several factors linked to the experience of mental distress are identified which can limit people's ability to participate, particularly in formal meetings. Therefore structures need to be flexible and responsive to individual needs. For example, minutes and papers may need to be put onto audiotape, meetings timed around public transport constraints and jargon minimised. The nature of some mental health problems is episodic; therefore systems need to accommodate this, perhaps by ensuring that participation involves as many people as possible. A challenge exists for managers to view service user and carer needs and demands as drivers rather than constraints— as opportunities rather than threats.

Training, support and personal development

The presence of a process that permits a transition from being *only* a service user to then taking on different roles eventually leading to paid employment through work experience, training and personal development programming (Truman & Raine, 2002) will facilitate development.

Policy (and resources) on support, systems and mechanisms that are put in place will assist people to best cope with the demands related to involvement (Simpson et al, 2002; Truman & Raine, 2002). These demands may be about (1) people coping with new roles and responsibilities (2) meeting and being with unfamiliar people (3) communicating differently (4) coping with travel, managing time, personal organisation and (5) balancing involvement with other personal responsibilities.

Clear policies and agreements on the reimbursements for expenses and for the time given to participation and the methods used for receiving payments are important (SDC, 2001; Ryan & Bamber, 2002). It is advocated that payment should be made not only for expenses and time given but also for child care, sitting (e.g. for older people) and/or respite care (Ryan & Bamber, 2002).

Staff training and development

Staff training and development have been identified as an important area of activity to support involvement. This means ongoing staff training to inform and educate about service user and carer involvement (Carr, 2004) and for this to include all staff within an organisation and not just those at a managerial level (Poulton, 1999). It also means appropriate recruitment, training and support for staff in equality and diversity issues and anti-oppressive practice which will then underpin effective progress in ensuring involvement, followed by ongoing training and support (Aitchison, 2001) and rewarding staff for achieving service user- and carer-focused goals (Basch, 2002).

Monitoring and evaluation

The presence of a robust monitoring and evaluation system that looks at the impact and auditing of the change that has taken place as a result of involvement rather than only analysing the process will contribute to strengthening involvement (Robson et al., 2003; Audit Commission, 1999). Any monitoring should involve independent service user and carer groups (Poulton, 1999) and the outcomes (Crawford et al., 2002) such as comparisons of approaches and the evaluations of suggestions/decisions made by users service users and carers.

2.5 Issues and factors to be avoided

It is fairly obvious that the factors which the literature identifies as factors that need to be avoided are the converse of those previously identified. Themes which repeatedly emerge are:

- Lack of purpose and clarity about the expected and actual outcomes from involvement
- Poor information strategy
- Lack of autonomous service user and carer groups
- Lack of resources to support involvement
- Organisational and staff attitudes meaning that involvement is not a priority and views dismissed. This is not helped by a high turnover of staff and a lack of staff that understand the value and place of service user and carer involvement.
- Insensitive organisation and style of meetings: for example inaccessible venues, formal style of meetings etc.
- Lack of support to enable people to fully participate
- Lack of attention to diversity

2.6 Involving diverse groups of people

Additional consideration is needed to effectively involve diverse communities and groups with different cultural norms and expectations. This section considers both the general guidelines that can be found in the literature and specific issues for the key groups. **This is not a comprehensive review of the specific needs of different minority groups and there are perspectives that have not been considered** (for example employment status, disability, geographical location and specific mental health issues e. g. those with a diagnosis of personality disorder or Alzheimer's disease). It is included to illustrate the way in which involvement is structured can discriminate against a particular group of people and that flexible and creative ways of engaging with different groups need to be sought. It is therefore recommended that NIMHE commissions a review of the literature and good practice (including codes of practice – see the Disability Rights Commission for example) in relation to engaging diverse and minority groups. This would provide a basis for developing a set of standards to support the involvement of a diverse range of service users and carers in different aspects of NIMHE's work programme.

General principles for involving diverse communities and minority groups

- Understand the additional discrimination minority groups encounter and take action to tackle discriminatory attitudes.
- Ensure that the organisation reflects the diversity of those with whom it is seeking to engage.
- Undertake staff development and training in diversity.

- Allow greater time for everything: finding out about and making contacts with different groups, bringing people together and providing the appropriate support to become involved.
- Think about imaginative ways of working with people and work with communities and those who have a track record of engaging with the specific community or minority groups, including work with independent advocacy groups.
- Provide information in accessible formats, in different languages and appropriate to the culture of the community or the minority group concerned.
- Provide specific training and support to become involved, e.g. provision of childcare, access to same sex members of staff especially for personal support issues.
- Monitor the impact of the action that has been taken in terms of facilitating involvement.

Black and minority ethnic communities

The individual and institutional racism which people have experienced in their relationship with mental health services needs to be understood in relation to involvement. Black and minority ethnic (BME) communities are not at the same starting point as other service users and carers. This is confirmed by the recent survey by Walls and Sashidaran (2003) which found that for these communities, approximately half of those using mental health services had experienced racial discrimination. This rose to two thirds for black people who had experience of services whilst 78% of black people in general saw staff racism as a problem in mental health services.

The forthcoming framework developed by Ferns: A Journey to Participation-Letting Through The Light, outlines the pitfalls to be avoided and a process for involving BME communities in service improvements and developments.

Other factors identified in the literature which need to be considered are:

- The use of language and its interpretation, which may have different or no meaning in different cultures/races/nationalities such as the words “stress” and “healthy life-style” (Rudat 1994).
- The employment of BME staff (Crawford et al 2003) and the presence of black worker groups (Social Services Inspectorate 2000) will both have an impact on the likelihood of the involvement of BME service users and carers in an organisation.
- The opportunity to participate in cultural competence and race awareness training has been highlighted as beneficial (Walls & Sashidaran, 2003).
- In general, working with the community was the best way to promote engagement (Walls & Sashidaran, 2003). Community organised groups based on religion are relatively easy to access and these groups have the potential to make useful links (Crawford, 2003). Further added value can

be had from contacting BME organisations that have not previously been seen as main players and which could easily be overlooked (Johnson, 2002).

Steps to facilitate BME involvement which have been identified include:

- Making links with advocacy services that work with BME people (Crawford et al., 2003).
- Making links with health link workers (Tang & Cunningham, 1994) and health advocates (Rai-Atkins, 2002).
- Organising “open events” that were targeted at specific BME groups (such as the Chinese, Irish or Asian communities) have been found to be particularly fruitful (Walls & Sashidran, 2003).
- The use of a questionnaire for completion by individuals at other types of activities/community events/research activities has been shown to enable people to express views where they may not feel inclined to do so within an interview or focus group (Walls & Sashidran, 2003).

Children and Young People

A major barrier for the involvement of children and young people is attitudinal. In particular there is a need to overcome the belief that the views of children and young people do not matter (McNiesh & Newman, 2002 & Danso et al., 2003); that children and young people act irresponsibly and selfishly and that they will therefore only focus on their own issues rather than being able to think more widely (Hill et al., 2004) or that children and young people will find involvement to be too taxing or upsetting (Crawford et al., 2003). The culture of the organisation is a key determinant of the effectiveness of children and young people's participation (NCB, 2002). Key to involving children and young people is:

- Placing the emphasis on their own perspectives (Christianson, 2004).
- A recognition of the need for careful interpretation of what children and young people say and what they mean (i.e. what is said is not necessarily what is meant) especially in terms of the perception and understanding of words in different contexts (Sinclair, 2004).
- A need to focus on the issues that are important to children and young people in order to ensure motivation, relevance and participation (Davis & Edwards, 2004 & McNiesh & Newman, 2002).
- A need to recognise the dangers and limitations of sticking to working with the “favourite” groups, which are usually older children (Hill et al., 2004) and similarly the need to include those children and young people who are more likely to be excluded specifically younger children, those with communication difficulties and those with minimum involvement with agencies (Sinclair, 2004).
- Children and young people need to feel in control of the process of involvement and also in specific projects (Christianson, 2004).

- Working with advocacy groups on involvement issues (Crawford et al., 2003).

Ways of working with children and young people which have been identified include:

- Producing videos etc. (Wardale & Trooke, 2003)
- Using newspapers/newsletters etc. and pen pal schemes as a “virtual” forum for campaigning (Crawford et al., 2003)
- Community fun days (Donnelly, 2003)
- Phone lines as a means of getting feedback and obtaining views (Crawford et al., 2003)
- Accessing children and young people at alternative venues such as schools and youth groups where accessibility is relatively easy (Crawford et al., 2003)

The National Children’s Bureau currently has a project looking at the participation of children, of all ages, in service planning and development.

Older people

Similarly to the involvement of children and young people, attitudes are a major barrier for older people particularly ageism (JRF, 2004). Those that have been specifically identified are the belief that older people cannot perform certain tasks and activities such as those that are part of effective participation (Lewis, 1997), should be grateful for what they receive (Crawford et al, 2003) or are all incapacitated (Crawford et al, 2003). The level of involvement of older people consequently in national and local initiative remains low (JRF, 2004). Initiatives such as Better Government for Older People, established to develop the involvement of older people in service planning and delivery and the Older People’s Reference Group (HOPE) to the National Service Framework are indications that older people are beginning to have a stronger say. The experience of these and initiatives in the voluntary sector, for example Age Concern and Help the Aged, are important to draw upon. The joint statement from the Nuffield Institute, ADSS, Local Government Association, Audit Commission, Better Government for Older People and the Joseph Rowntree Foundation (2004) recommends generally raising the profile of older people. It advocates better coordination across government departments to develop a coherent framework of decision-making and accountability in relation to older people.

The literature on involving older people, particularly those with Alzheimer’s appears to be limited in comparison with other areas of involvement. The key messages include:

- Secure funding for organisations working with older people as a basis for strengthening involvement (JRF, 2004, Crawford et al 2003) and

resources to support existing groups to develop activities and broaden membership

- Making links with community groups and activities such as luncheon clubs (Crawford et al, 2003)
- Starting with people's lives and stories (JRF, 2004)
- For very frail older people involvement from home as a base can work well (Crawford et al 2003).
- Staff development and training to enable proper engagement with older people (Crawford et al 2003).

The Joseph Rowntree Foundation (JRF, 2004) proposes that the meaningful involvement of older people requires standards:

- On the numbers of older people involved
- The stage of development when they are included
- The resources to support them becoming involved
- The involvement through out the whole process

People with a learning disability

The Valuing People Support Team and NIMHE have developed guidelines on involving people with mental health problems who have learning disabilities. This builds on an inclusive approach, and people with learning disabilities have advised policy makers that there should be “nothing about us without us” (Department of Health 2001).

Some key issues which have been identified (Gregory et al 2003) are:

- It may take time to identify, locate and bring together a group of people with significant experience of mental health support, including those with experience of mental health service provision, to get their perspective.
- The concepts “mental health”, “mental health problems” and “mental illness” are complex and may not have been explored very much with people who have learning disabilities: people may need time to think about what they mean. Finding the right words to use, that mean something to people, is a critical starting point.
- Including people in mixed discussion forums with non-learning disabled people before they have had much chance to consider the issues and what they want to say may effectively “exclude” them from making an effective contribution.
- People need time to feel comfortable in groups, and to think about the issues being discussed. The picture will evolve and become more comprehensive and informative over time.
- Groups will need facilitators who can use approaches and techniques that get the most out of people. The facilitators will need knowledge and skills around mental health as well as how best to support people with learning disabilities to communicate and contribute their views.

Practical issues which have been identified include:

- Using plain language
- Listening carefully and valuing people's contributions
- Talking to people one to one, in private, if someone prefers
- Using visual and audio formats to aid communication
- Having easy to read summaries of written documents
- Funding support workers
- Giving people adequate information and time to prepare their responses
- Going at a pace that allows people to take part
- Creating a relaxed and comfortable atmosphere in meetings, with regular breaks

A more detailed framework is provided by Aitchison et al (2003).

Gender

There needs to be a consideration of the specific needs of men and women. It is well recognised that the use of language and the participation of the different genders in groups is skewed towards men with findings that men are consistently more assertive in public situations and confrontations (Kimble et al, 1984, cited in Borrill et al, 2001). Whilst this may be changing the expectations about communication and communication style may differ for men and women. In addition significant numbers of women who are using mental health services have experienced abuse which may mean it is more appropriate for women-only discussions of some issues (Department of Health, 2002).

Other issues which have been identified include:

- Venues need to be safe and accessible and provide child care
- Consideration of gender-specific approaches, particularly in relation to specific issues and for hard to reach groups of either gender
- The use of a wide range of methods to ensure that there is the opportunity for a broad spectrum of both men and women to be involved
- Using existing meetings and venues such as those for parents and toddlers is one way to make contact with people
- Training on gender sensitivity
- Access to same sex members of staff particularly for personal support issues.

Lesbian, gay and bisexual people (LGB)

Little has been written on involving lesbian, gay and bisexual people. The key issue is how best to target LGB people to facilitate their involvement and ensure that their issues are included on NIMHE's agenda. A snowball method developed by King & McKeown (2003) has real potential in reaching out to LGB people and other groups. It involves initial recruitment through a range of strategies:

- Advertising in the LGB and mainstream press
- Postcards and leaflets advertising the study were left in gay pubs and venues
- Mailings to gay and lesbian societies and placing advertisements on LGB websites
- Placing posters and notices in health clubs and libraries

The second wave involves asking each first wave participant to pass postcards on to a friend who might be interested in getting involved.

This section does not provide a comprehensive review of the issues for different minority groups. It points to **some of the issues for some of the groups** and there is much that is missing. It does however serve to illustrate that if diversity is to be broadened then NIMHE needs to develop an understanding both of the particular nature of discrimination for the group concerned, take steps to ensure that this is not reflected in the way that involvement is approached and develop methods which are meaningful and appropriate for the group concerned.

Summary

A lot has been written about involvement, particularly the involvement of service users. It points to:

- ***Being clear about the purpose of service user and carer involvement so that everybody understands why people are involved and what can be expected.***
- ***Involving service users and carers in different ways and at different levels of the organisation including involvement in decision-making.***
- ***Understanding and addressing the barriers which limit the involvement of service users and carers including attitudinal, practical and personal barriers.***
- ***Ensuring that the organisational culture, the ways it works and is organised are designed to facilitate involvement.***
- ***Training staff so that they understand service user and carer involvement and are well versed in anti - oppressive and inclusive practice.***
- ***Having a good information strategy so that people know what they can become involved in; how decisions are made, and mechanisms to provide regular feedback on the outcomes from involvement.***
- ***Ensuring communication is clear, unambiguous, easy to understand and accessible.***
- ***Ensuring flexible and appropriate support for service users and carers who become involved including ongoing support systems and mechanisms, payment and reimbursement of personal expenses***
- ***Linking with community groups, using different methods to reach different community and minority groups.***
- ***Working in partnership with other organisations which have specific experience and skills in engaging diverse and minority groups.***
- ***The need for ongoing support, monitoring progress and achievement as a result of the steps put in place.***
- ***To broaden diversity NIMHE needs to develop an understanding both of the particular nature of discrimination for the group concerned, take steps to ensure that this is not reflected in the way that involvement is approached and develop methods which are meaningful and appropriate for the group concerned.***
- ***It is recommended that NIMHE undertakes a more comprehensive look at the literature and available good practice to set a set of standards to guide the involvement of a diverse range of people in its programmes.***

Chapter 3 Summary of Findings

3.1 Service User and Carer Involvement in NIMHE

Service users and carers are employed by NIMHE at a national and regional level on a full-time, part-time or job-share basis. They can be found mainly in three key roles: as Regional Leads for service user and carer involvement, as Fellows and as Champions⁴. In addition there is:

- Involvement in events and conferences: as delegates and as speakers/workshop facilitators
- Involvement in work programmes, at national and regional level, and associated meetings
- Membership of the national Experts by Experience Group
- Membership of Regional Forums/Reference Groups and/or service user/carer networks
- Membership of Regional Development Centre Management or Advisory Boards
- Representing the NIMHE RDC, in particular the service user or carer Regional Forum/Reference Group
- Training and capacity building: both providing and participating
- Involvement in research: both as researchers and as research participants
- Involvement in consultation exercises
- Involvement in the recruitment process for NIMHE staff
- Involvement in selecting successful bids for pilot projects, research projects and education and training programmes
- Stakeholder evaluation to inform annual work programmes
- Involvement in the development of guidance and information packs

The most common form of involvement identified by those who returned the questionnaires is involvement in conferences (77%), membership of committees (37%), meetings (31%) and networks (28%). Obviously fewer people but still significant numbers identified working for NIMHE on a paid (15%) or unpaid basis (10%) or being involved in an interview panel for recruiting staff (8%).

⁴ Appointed as Service Development Champions, not specifically service user champions.

3.2 Overall Assessment of Involvement in NIMHE

“Actions speak louder than words.”

“It is getting better but could still be improved: our opinions need to be valued and appreciated. Personal experience is of considerable use in planning for the future.”

“It’s excellent that the input is valued.”

“They are trying very hard to do it.”

The picture is mixed. There was an acknowledgement that NIMHE has made some real efforts to develop service user and carer involvement both at a national and regional level within a relatively short space of time. In particular the steps that NIMHE has taken to employ service users and carers were welcomed.

The assessment of NIMHE’s performance on involvement inevitably reflects both an individual’s experience and his/her aspirations. In general the assessment of NIMHE’s performance at a regional level was more positively evaluated than at a national level. Secondly there was a discrepancy in some instances between the assessment by staff and those of service users and carers with a tendency for staff, particularly programme leads, to be more positive about both the impact of involvement and the efforts NIMHE has made. The responses to the questionnaire also tended to be more positive than comments made during individual interviews and focus groups. (On the questionnaire 55% of service users rated their experience positively compared with 27 % who rated their experience as mixed and 13% who rated it negatively. Similarly 53% carers rated their experience positively compared with 31% who rated it as mixed and 13% who rated it negatively⁵.) In the focus group and interviews respondents clearly identified a range of shortcomings in NIMHE’s approach to involvement which are discussed below.

There is clear evidence of NIMHE’s commitment to involving service users within the organisation from the intent of policy documents, from investment in supporting involvement and from the information received about the different ways people are currently involved. A key issue is how NIMHE strengthens this commitment so that it is tangible to service users and carers, more systematic and more broadly based within a diverse community of interest. Whilst some service users have a “voice” within NIMHE, some are noticeably absent, particularly those from black and minority ethnic communities, older and younger people, people with a learning or physical disability and those who have a diagnosis of personality disorder.

The involvement of carers is not as well developed; there is less investment in terms of resources and they are in general less involved across NIMHE’s different work streams. Carers not only come from different community and

⁵ The remaining percentages did not respond to this question

minority ethnic groups but there are also important differences in the nature of the caring relationship: parent-child, siblings, child-parent, which have not necessarily been taken into account.

The commitment of those who are striving to create effective service user and carer involvement in NIMHE was also commented upon. However this was tempered by the widespread frustration and disappointment at the apparent lack of impact that this involvement was having and in particular the sense of exclusion from decision-making. Service users and carers currently have little established power to set the agenda and influence and affect decisions. Further there do not appear to be any areas of NIMHE's activity where they have overall control.

It is worth noting the complexity of the task. NIMHE is a large organisation with a diverse range of activities and involving service users and carers well will take time, sensitivity and resources. Further NIMHE, in its current form, is only two years old and two of the regional development centres have been established in the last twelve months. In formulating an assessment, fundamental questions were raised about the nature and organisation of NIMHE, how well it is performing in general and the scale of expectation, and consequently workload.

Eight main themes emerged in relation to NIMHE's overall performance. These are:

A lack of awareness of NIMHE

"Who?"

"Generally very hard to know what NIMHE does. I only learnt through a committee meeting and putting myself out to look at a website."

"It would be very useful for a NIMHE rep from the regional development centre or team member to come and give a talk to the local forum or user organisation on the work of NIMHE and how to get involved."

"There needs to be effort, resources and time spent on telling people about the differences and impact that involvement can make."

Many of those who participated in the focus groups had obviously not heard of NIMHE or the local RDC. This was particularly evident at the focus group aimed at black and minority ethnic communities (BME). Of the 230 plus people who attended only a handful had heard of NIMHE. In contrast 75% of those responding to the questionnaire had heard of NIMHE with over half hearing about NIMHE through service user or carer networks.

Associated with this, a number of people commented on the difficulties in conceptualising and articulating NIMHE's role. Capturing and conveying the complexity of development work for an organisation which is essentially at arms-length is not an easy task. Communicating this to people who are deeply

dissatisfied with services, and whose first language may not be English, requires both time and skill.

It is clear that straightforward accessible information needs to be provided about NIMHE in a variety of formats and other languages. The reliance on the Internet and electronic communication was frequently referred to as limiting potential involvement. The central role of existing service user and carer networks in disseminating information about NIMHE (and vice versa) needs to be strengthened. The value of reaching out to different minority groups and communities was also emphasised. When this happens the information can be more precisely tailored to the needs of specific groups. The value of working with other organisations and the voluntary sector who have an established track record in working with a diverse range of groups, for example Barnado's and the National Children's Bureau in the work with young people or Age Concern and Better Government for Older People in their work on involvement and older people, was signalled.

The role of NIMHE in relation to other organisations

"We are all fishing in a small pool"

A number of service users and carers raised questions about how NIMHE is different from and/ or relates to other national organisations particularly the Commission for Public and Patient Involvement, Patient and Public Involvement Forums and the Healthcare Commission. Some service users and carers had been encouraged to get involved in more than one of these and it was often not clear to them what differential impact their involvement might have. Examples not only of confusion but also duplication of effort were given. At the time this work started there would not appear to have been discussions between NIMHE and these organisations, and indeed others, as to how they might work together to make the basis for involvement clearer. This confusion about the role and function of the different organisations is acknowledged by those in senior management roles pointing to the need for NIMHE to clarify their approach with these other organisations and establish how they might work together. More recently steps have been taken in London to establish a network of London Mental Health Trust PPI Forums which is linking with NIMHE.

The role of NIMHE

"It's a toothless tiger"

"People don't seem to understand the role: it is about supporting the implementation of national policy"

"Shouldn't service users and carers be working in partnership with NIMHE to do something about the barbaric treatments people receive?"

Questions were raised about the role of NIMHE, mainly about the extent to which it could influence and shape local provision but also what it could do to improve the civil status of people with mental health problems. Many service users and carers want to change the experience of services for people. How NIMHE aims to achieve this is unclear and there were many calls, particularly from carers, for NIMHE's role in relation to performance management to be strengthened. In addition NIMHE's power in relation to decisions about priorities and how money is spent in services is perceived within NIMHE as being limited.

This is further compounded by some complex contradictions for NIMHE in involving service users and carers. The most fundamental of these is the central drive to implement national policy in contrast to taking action on a service user- and carer-defined agenda. Linked to this is the emphasis on robust public and performance management not sitting easily with service user- and carer-defined outcomes. Reference was made to NIMHE's potential role in relation to the draft Mental Health Bill to illustrate these tensions.

Service user and carer involvement is marginal to NIMHE

"It is a huge challenge for those in high places in NIMHE to talk to us and sometimes they succeed and sometimes all their efforts do is further enrage us. We need to be more than a bum on a chair and a tick box score."

"Don't place us in the position of being odd from the outset. Don't set us in isolation because we express ourselves differently from the business world."

"I believe that service user involvement in NIMHE has to be fundamental to its continuation."

"The service users have a "strong say" and autonomy on a day to day basis."

"Service users and carers are being skilfully disregarded by NIMHE with the exception of some highly skilled and able individuals."

Some service users and carers do indeed feel that they can have their say. However service user and carer involvement is seen by the majority as not embedded within NIMHE. Disappointment and frustration at the powerlessness of service users and carers to influence decision-making within NIMHE were widely expressed not only by service users and carers but also by staff working within NIMHE including managers. Involvement was often referred to as "*an add-on, tokenistic, marginal and hit and miss*". This was exacerbated by the sense that statements of intent from NIMHE have not been matched with sufficient attention to making service user and carer involvement a reality. However this view was not universal and clear examples were cited where involvement had made a

difference to decision-making, for example an RDC's policy in relation to pharmaceutical companies.

The lack of feedback, referred to by many respondents, will confirm feeling marginalised and mean that the impact that service users and carers actually may have had remains hidden.

A number of respondents wondered whether NIMHE's position in relation to service user and carer involvement reflected an underlying ambivalence about involvement which characterises the Department of Health. This raised questions about the purpose of involvement, what outcomes are being sought and what would count as success.

Purpose of involvement with NIMHE

"Are we the hamster in the gilded wheel?"

"We are at their mercy"

"There needs to be a genuine improvement in the care that people receive"

"Service user and carer involvement is at a crossroads and many things that have driven the need for involvement, such as 24 hour crisis intervention, have been achieved. It is nowtime to regroup and look at how services can be tailored to individuals."

"Involvement is not just an end in itself, it is also a means to an end - the 'end' being the achievement of effective outcomes, that things are better as a result."

As a result of the issues identified above many of the service user and carer respondents thought that the purpose of their involvement in NIMHE was unclear. Many voiced the aspiration of wanting to influence the decision-making within NIMHE; for their views to be listened to in order to bring about changes in services; to have a tangible impact at grassroots level to the experiences of service users and carers on the issues that matter to them by shaping what NIMHE does.

Relationship between NIMHE at a national level and the regional development centres

The importance of the regional development centres and their role in supporting policy implementation at a local level was stressed. They are clearly well placed to understand the local context and to build meaningful relationships with local service user and carer groups. Service user and carer involvement has consequently evolved differently across the eight RDCs. This should not be interpreted as necessarily problematic. However there are a number of important differences which can be interpreted as inconsistencies in NIMHE's approach

and can be confusing to service users and carers who may well network with service users and carers from other regions. These are:

- Level of investment in service user and carer involvement
- Different payment policies
- Level of influence of RDC service user and carer leads
- Differential rates of pay for RDC service user and carer leads

These differences suggest that the corporate understanding of service user and carer involvement within NIMHE is not well developed and that a common approach on these issues in particular would be helpful.

Involvement in governance arrangements

“We are involved in the RDC governing body – so involved in developing the RDC work plan.”

“Service user involvement has grown from a token service user on the board to 3 service users and 2 carers with a vacancy for another carer.”

“We cannot do our jobs unless we have the support of people, on whose behalf we work”.

Service users and carers are increasingly involved in the governance arrangements for NIMHE at a regional level. The majority of the NIMHE RDC Boards have several service users and carers as members. These members do not necessarily represent other service users and carers although may well be part of Reference Groups or Regional Forums. At a national level, NIMHE has an Executive Group which is mainly made up of the RDC Directors. There is no service user representation on this group. In the development of NIMHE, a NIMHE Council was established and this was to have the executive function. However this was reconstituted in the light of the development of the regional development centres to form the National Strategic Partnership (NSP). This group is chaired by a service user and it now has an advisory function. Its relationship with the NIMHE Executive Group is not clear. The EbE group is purely advisory and does not have formal involvement in the NIMHE Executive, although is represented on the NSP.

An apparent lack of inclusiveness

“It’s always the same people”

“I believe that user involvement should be open and accessible to all”

“Carers should be respected and allowed to get more involved.”

“Systems need to be in place so that NIMHE is not only involving service users in terms of numbers and diversity but that their involvement can be shown to be making a difference.”

“Why do the quiet ones not get a voice, the loudest get heard-what should happen to engage more people?”

NIMHE only contacts people when it wants something-to fill in questionnaires-little or no contact otherwise to keep people up to date with work and other relevant information.”

“We need to hear all voices but please let us hear the voices of Hope and Success, voices of recovery not simply voices of disability”

The apparent lack of inclusiveness in NIMHE’s approach was a recurrent theme and there was a widespread concern that NIMHE is not engaging with a diverse range of people. There were a number of aspects to this. Firstly there was a widespread concern that NIMHE continues to draw on the same group of people who then become “professionalised” and may not be well connected to local groups.

Secondly attention was drawn to the poor engagement of people from a whole range of different minority groups and their under-representation: black and minority ethnic communities (BME), people with a diagnosis of personality disorder, young people, older people, people from primary care, people experiencing anxiety and depression, people with severe and enduring mental health problems, asylum seekers and refugees were all mentioned. It is worth noting that little mention was made of people with physical disabilities or sensory impairments, people with learning disabilities and gay, lesbians or bisexuals, prisoners with mental health problems or people in forensic settings, although carers of the latter were mentioned as being overlooked. Although identified as an issue, there was however not a lot of evidence that NIMHE had actively and systematically sought out involvement from the different groups and understood what it needs to do to secure this engagement. The lack of involvement of diverse groups, and focused attention to developing it, was therefore consistently interpreted as evidence that there is active discrimination in the way that NIMHE has chosen to operate and the priorities it has established.

Thirdly NIMHE as an organisation and its modus operandi was viewed as being exclusive. For example the ethnic and gender profile of the RDC Directors was cited as reflecting discrimination within NIMHE. The way NIMHE typically operates in formal meetings and the associated group dynamics were also described as being more comfortable and familiar for some than others to manage, e.g. for men than for women, those with higher level of educational attainment or work experience and may actively exclude some people, specifically those with a learning disability or people who are not fluent in English. There was a call for NIMHE to reflect on this and to develop more creative and flexible ways of engaging with people.

Finally there was a concern that many of the people who are currently engaged are, or represent, secondary care service users leading to the challenge that NIMHE is equating service user involvement with involving people that the

system has disempowered. A broader definition of service users was advocated to include “*people who have found a way out for themselves*”, consistent with the philosophy of recovery to which NIMHE aspires.

What difference is involvement making?

In general there was a widespread view that involvement had had little impact on the decision-making process and the work of NIMHE. 30% of those who responded to the questionnaire thought that their involvement had had no impact compared with 17% who thought that they had had an opportunity to promote change. This was most frequently attributed to the role of NIMHE in implementing national policy leaving little space for a service user- and carer-generated agenda. From the interviews and focus groups, the main impact of involvement which was identified was in relation to NIMHE staff. Firstly the involvement of service users and carers in recruitment was seen as positively influencing the staffing profile of NIMHE. Secondly that service users and carers working alongside staff had helped to shift attitudes about the potential of service users and carers and develop a richer understanding of service user and carer issues. Respondents to the questionnaire also identified personal gains for example gaining information, feeling valued and developing confidence.

3.3 What is NIMHE currently doing that is working well?

“Energy follows, work gets done”

There is much good practice to draw on and in this section we cite a limited number of examples. There is real interest in the good practice as it is developing and there needs to be a way of NIMHE collating it, sharing it both internally and with others and reflecting on the learning from the difficulties and complexities of strengthening involvement.

Developing a regional infrastructure

Whilst there are significant issues about the way in which people are involved in NIMHE there was a sense that there had been a significant investment in terms of personal effort and in developing an infrastructure for involvement at a regional level. The responses to the questionnaire indicated that people found meeting other service users and carers, sharing views, being kept informed and being listened to, helpful aspects of NIMHE’s approach.

The purpose of involvement at a regional level appears to be clearer and working more satisfactorily than involvement at a national level. This includes the basis for recruitment being clearer, the connections with local networks being better developed, greater opportunities for involvement across a number of programmes and a more significant level of investment in making involvement work. Some RDCs have, from the start, given thought as to how they might best involve service users and carers and work with the local areas. North East, Yorkshire and Humber NIMHE have organised its staff team and the work of the

service user and carer posts to line up with the Strategic Health Authority configurations. This way of organising the RDC to fit local organisational structures is clearly helpful and is evident in other regions.

A number of the regions cover vast thinly populated areas. In the Eastern region there is an active e-mail discussion forum with 45 members contributing regularly. The South West faces similar challenges and has developed clear information routes, sending out a monthly news bulletin to keep people in touch and holding an annual conference.

In addition to these specific examples, the following were identified as areas of where NIMHE is perceived to be making progress at a regional level:

- Involvement in the recruitment and selection of staff
- Involvement of 2-3 service users and 2-3 carers on the Management Board
- Chairing/Co-Chairing of the Board by a service user or carer
- Annual stakeholder evaluation process to help determine the work programme for the coming year
- Learning from the experience of involvement and efforts to strengthen it
- Capacity building both through formal programmes and through providing a range of different opportunities to be involved as described below

Capacity Building

People were positive about approaches to capacity building and training initiatives which had been developed and there are some good examples. A number of RDCs are developing leadership courses for service users. We heard directly from service users in the South East how much this and the approach of the RDC to capacity building was appreciated and had contributed to the personal development of the service user participants. The East Midlands Regional Development Centre has developed a course called “Active Involvement” and is developing a second stage course which they aim to have accredited by the Open College Network. As a consequence of their ongoing involvement in the International Initiative for Mental Health Leadership, the Service Improvement Team, one of the national programmes, is designing a leadership project, in a process which involves service users and carers.

Strengthening Diversity

Many of the RDCs are making active attempts to strengthen the diversity of those involved. The London Development Centre for Mental Health is focusing on developing a wider pool of user associates on which the RDC could draw and have recently held a Participation Party which was well attended and has led to a number of expressions of interest in becoming involved. The potential role of the Race Equality Leads is clearly seen as an opportunity to improve the engagement of people BME communities. In the North West a post was created to develop networks and capacity building for carers living in rural and isolated

parts of Cumbria. In the Eastern Region, a group (Connections for Women) has been developed to look at the issues for women. The group meets on a regular basis, has an email group and has appointed a service user as chair. The West Midlands is also developing work to involve service users from primary care.

Payment policies

Although NIMHE does not have a single payment policy the RDCs have developed their own and these were mentioned on several occasions as working well, both by RDC leads and by service users and carers. The prompt payment of expenses is clearly valued. The policy which was developed by the West Midlands Policy was mentioned by several people as being exemplary and appears to have been used as a model by other RDCs.

Involvement in decision-making

A strong theme which emerged from interviews and focus groups was the desire to be involved in decision-making. Two notable examples were drawn to our attention: service user involvement in selecting the successful bids for Primary Care Graduate Mental Health Workers and for the Personality Disorder Pilots. The East Midlands Development Centre is leading on building service user involvement into the recently commissioned education and training programmes for primary care graduate mental health workers. The Personality Disorder Programme established a Service User Reference Group to involve service users with a diagnosis of personality disorder, in the selection of 11 pilots for people with a personality disorder diagnosis across England. The feedback received indicated that service users actively influenced the final selection.

In addition both the Personality Disorder Programme and the Mental Health Research Network have developed criteria for selecting successful bids, which assess the arrangements for service user and carer involvement.

3.4 Service user and carer involvement at a national level

The Experts by Experience Group

The EbE group was the first group that NIMHE established although in embryonic form it existed prior to the development of NIMHE. It was originally formed in response to a request from the National Director for Mental Health for a service user and carer group to be developed to advise a national group on outcomes. In developing the group, consideration was given to its membership and invitations were sent to national mental health organisations to nominate representatives. Subsequently the NSF Champions became members of the group and more recently it has recruited representatives from the regional development centres.

The group meets on a regular basis and is co-chaired by the NIMHE Chief Executive and a member of the group. Both service users and carers attend the meetings, although there has been tension between the different agendas and carer members tend to feel that the agenda is geared towards service users. In

recognition of this two subgroups have been formed but have not become firmly established.

The prevailing view is that the focus of the group is unclear and, despite its skilled and motivated membership, is not as effective as it has the potential to be. Some members commented that the EbE group had been put in an impossible position: that there is an expectation that it will influence NIMHE's agenda but it does not have the formalised authority or resources to do so. Consequently the group feels marginal to NIMHE.

Concerns were also raised by those external to the group. Specifically the name of the group, its role within NIMHE, its membership and lack of diversity and the apparent lack of transparency in recruitment to the group were all mentioned.

Purpose/focus of the group

The original focus which was outlined was:

- Responding to requests for advice from NIMHE
- Initiating items for consideration by NIMHE
- Making the best use of the skills and experience of the Expert Group to support the objectives of NIMHE

However, the purpose of the group is not entirely clear. On the one hand it is in practice viewed as providing a service user and carer voice into NIMHE. On the other as providing a forum for support and information sharing for those involved in NIMHE. These two could legitimately be viewed as separate functions. It clearly played an important role during the development of NIMHE and there is recognition both from its members and from external groups, that its purpose and focus needs to be reviewed.

Membership

There are currently 22 members of the group. The process of recruitment to the group is not clear to those external to it. The original membership included service users and carers who were well known in the field and some members have known each other for a number of years. Others have consequently found it hard to join in and felt excluded by virtue of the group dynamics. In addition the BME membership is acknowledged as being under-developed but little appears to have happened to address this. The recent development of regional representation is seen as strengthening the group in connecting it to local issues, although the lack of clarity about focus was identified as weakening the potential contribution. Finally the chairing arrangements attracted comment and a sense that these are not entirely satisfactory.

Resources

The group has no identified budget to enable it to raise its profile or to connect with other service user and carer groups. This obviously limits its potential.

Relationships and accountability

There are few formal links to NIMHE groups or to other service user and carer groups and therefore it is not clear where the EbE group sits in the NIMHE, or broader modernisation, world. However a number of members have positions as Fellows or Champions and are able to have an influence on some of NIMHE's work programmes through these roles. Four members of the EbE group sit on the National Strategic Partnership to provide a service user and carer voice.

Influence/impact

There is a strong sense that the group has had little impact upon NIMHE.

Role of the Expert by Experience Fellow

There are currently seven Fellows at a national level including the Experts by Experience Fellow. The Fellowships were established to:

"bring to NIMHE important areas of expertise, and enable the Institute to develop its practice and thinking beyond existing service models, and beyond services for adults of working age".

The EbE fellow is seen as the 'expert' in service user and carer involvement in NIMHE. The role potentially has a number of different functions:

- An internal support and development role: supporting the EbE group and service users and carers involved at a regional level
- An external leadership role: linking with external organisations and raising the profile of service user and carer involvement
- Consultancy and policy advisory role: advising on programmes from the service user and carer perspective
- Research and dissemination role: synthesising and disseminating information

It is essentially a leadership role. However the current post holder is funded for 2 days a week to work on both service user and carer issues. Since January 2004 she has had administrative support but does not hold a budget. As with the EbE group there are issues in relation to the clarity of the role, influence, impact and accountability.

Further the role is potentially confused by the existence of other leadership roles, for example the service user and carer leads for Service Improvement in the Modernisation Agency.

In addition to the EbE Fellow, there is a Fellow for Recovery. Similar observations might be made about his role in terms of clarity of role, influence, resources and accountability. This begs a wider question about the role of Fellows, in general in NIMHE and what place they have particularly as NIMHE matures. Arguably these roles provided an important function during the development of NIMHE in ensuring a focus on service user and carer issues.

Now that NIMHE has become established thought needs to be given to how these roles can become embedded within NIMHE and the role that service users and carers can play, particularly those emerging from leadership development initiatives.

National Strategic Partnership

The role of the National Strategic Group is laid out in its terms of reference as follows:

- To agree the organisation's priorities which it will expect to see addressed through national NIMHE and Regional Development centre programmes
- To agree the NIMHE annual business plan
- To review the performance of the organisation against the annual business plan
- To agree the NIMHE annual report
- To sanction appointment of Fellows of the Institute
- Through its constituent members, ensuring that there is wide consultation of all of NIMHE's stakeholder groups in shaping the direction of the organisation

The group meets three times a year. The membership of the group includes the RDC Directors, a representative from each of the RDC Boards, which potentially could be a service user or carer, and four members of the Experts by Experience Group. The Partnership is chaired by a service user.

The group is perceived as having relatively little power which is seen as resting with the Regional Directors who form the majority on the NIMHE Executive. There is a lack of clarity about getting items onto the agenda and the way in which the group influences NIMHE.

Involvement in research

The Mental Health Research Network has established a principle of involving service users and carers at all stages in the research process. In order to meet this aim SURGE has been created. This is essentially a collaboration between the Mental Health Foundation (where it is based), a disability charity, "Shaping Our Lives"; the Experts by Experience Group and the Survivor Research Network. It is a newly formed organisation and aims to develop the capacity of service users to be involved in research and encourages service users to lead on project proposals.

Involvement in national programmes

Whilst this was valued by individual programme leads, the recruitment to and involvement in national programmes varied and appeared inconsistent.

The Service Improvement Team aims to work in a way which enables service user and carer involvement in all of its work streams and works with local

services to ensure that not only are service users and carers involved in transforming local systems but that there are also opportunities for leadership development. The Team also developed a process for recruiting service users and carers to be involved in designing and overseeing a leadership programme for service users and carers.

Two of the national programmes, the Primary Care and Personality Disorder Programmes, seized the opportunity of new developments to secure involvement. Other programmes did involve service users and carers (predominantly service users) in consultation, programme meetings and national events. The Recovery programme, arguably, provides a framework for involvement but this programme does not have an identified budget. Equally the work in relation to the Social Exclusion report was also identified as a significant opportunity to strengthen involvement.

NIMHE national annual conference

The NIMHE conference was seen as providing an opportunity for service users and carers to meet each other. However there was considerable criticism, particularly of the 2004 conference and included:

- No clear criteria for allocating free places so some people missed out
- Little space for service user and carer issues
- Dominance by professionals in conflict with the commitment that service users and carers should be at the centre of everything
- The venue was inaccessible for people with mobility or childcare issues

3.5 Service user and carer involvement at a regional level

NIMHE was described to us as “a federated structure” with eight regional development centres. This implies collaboration between the eight regional development centres around a common objective i.e. to improve the quality of life for people of all ages who experience mental distress. It also implies that the RDCs will have a significant degree of autonomy in the way that they operate and indeed this is reflected in the review of the ways in which service users and carers are involved at a regional level. There have emerged different models for service user and carer involvement but they tend to have the following characteristics:

1. One or more individuals who have responsibility for coordinating service user and carer involvement for the RDC. These may be full-time posts or several part-time posts and the majority of the post holders have experience as service users or as carers. In one instance a voluntary sector organisation has been commissioned, prior to the development of the regional development centre, to provide this function. The post holders may have additional responsibilities and this was more likely to be the case for carer leads although increasingly a number of the service user

leads appeared to be picking up responsibilities around the social inclusion and recovery agendas.

2. Service user and carer networks which are typically organised as a reference group of service user and carer issues chaired by someone other than the lead. In all but one instance the groups for service users and carers are separate. The organisation of these groups may or may not reflect other significant organisational boundaries particularly those of Strategic Health Authorities. Where there are vast geographical distances involved, the network may be more of a virtual one relying on e mail communication.

Resources to support involvement

In most instances the leads are not budget holders and although this may not necessarily impede access to resources it was, in some instances, seen as limiting involvement and the role of the lead. Basic information about expenditure was collected from each of the RDCs about the level of investment in involvement. This proved difficult to interpret as two of the RDCs were only recently established so they had to estimate costs based on the budget for the current year. Further the figures supplied also varied in terms of whether they included involvement in a range of programmes across the RDC as well as specific posts. However recognising that this might be an underestimate, NIMHE is investing in the region of £800,000 per year at a regional level in involvement. In general, more is being allocated to facilitating service user involvement (£510,000) than carer involvement (£300,000). What also emerges is the different ways that the RDCs are investing in involvement with one RDC investing heavily in capacity building. There are variations in the overall amount invested ranging from approximately £50,000 to £155,000. It was not clear what percentage of the total RDC budget this represents.

Service user and carer leads

Each of the RDCs is hosted by another organisation. Four are hosted by a specialist mental health trust, three by a Strategic Health Authority and one jointly by a n SHA and a mental health trust. The hosts provide a number of functions for the development centres including human resource functions. The recruitment of some individuals to service user posts, in particular, had raised an issue as to whether the policies of the host organisations were robust enough to facilitate this.

The variations in salary between the different RDC leads were also highlighted by the audit and referred to on more than one occasion during interviews. This cannot entirely be accounted for by the differences in roles and responsibilities across the RDCs. Inevitably it can be perceived as an indication of how seriously the particular RDC is taking involvement. Attention was also drawn to variations in salary between that of service user and carer staff and other RDC staff in

similar roles with a perception that service users and carers may be being discriminated against.

People working in service user and carer lead roles for NIMHE are likely to be experiencing mental health problems or caring for someone with mental health problems. The necessary adjustments or considerations which need to be made, do not appear to be routinely considered. For example, a number of the service user leads felt that the RDC Director would be sympathetic to any adjustments which would need to be made arising from their mental health problem, but this had not been formalised.

Role

The role of service user/ carer leads varies and in several regions the role of the service user lead, in particular, has been broadened. In general the role of the leads is:

- To coordinate and facilitate service user and/or carer activity
- To develop and strengthen involvement within the regional development centre and its programmes
- To facilitate the involvement of service users and carers in their local networks and in the work programmes of NIMHE
- To establish consultation exercises

A number of the leads whilst recognising the importance of the focus were concerned that service user and carer issues were not marginalised. They advocated that the responsibility for involvement needed to be embedded in the role of other programme leads as well. Some were concerned not to be 'typecast' and had therefore sought opportunities to broaden their role. However in general little thought would appear to have been given to career development.

The difficulties associated with the service user role in particular were highlighted on a number of occasions. Specifically, attention was drawn to the conflict of loyalties service users can experience in being employed by NIMHE. Again concerns were expressed about the role that NIMHE may play in supporting the implementation of the Mental Health Bill.

Position within the RDC

There are variations in relation to the inclusion of the leads within the management structure. Leads in general felt that they had more influence when they were part of the management structure and were accountable to the RDC Director than when they were not. The relationship with colleagues, particularly programme leads, is not clear and therefore the role of the service user and carer lead in supporting service users' and carers' involvement in specific programmes was often vague. Leads wanted to be consulted as a matter of routine by other programme leads but this is not generally happening.

Capacity

Until recently the posts have been limited to 1 or 2 people per RDC and this has contributed to people feeling that service user and carer involvement is a token. In some RDCs the capacity is currently being strengthened. In others however, the capacity is not being strengthened and in at least 3 of the RDCs the lead for carers is carrying a significant additional workload thereby limiting the time and focus it can be given. Also, the heavy workload and role that leads are expected to play means that there are real risks in terms of people getting 'burnt out' and leaving. A number of service user and carer leads described working more hours than they are contracted for and this is typically because they are supporting other service users and carers and/or survivor workers struggling in their roles. Several service users and carers expressed concern for the workers and the position that they have been placed in; seen as managing the demand and expectation from service users and carers while not having the necessary authority and resources.

Support

Supervision, appraisal arrangements and team meetings are generally in place with some leads also having external supervisors/mentors. NIMHE RDC Directors were perceived as being responsive to requests for training and development although personal development needs do not appear to be universally considered.

Whatever the arrangement it was clear that this support was welcomed and concern was therefore expressed when the regularity of supervision proved spasmodic. Meetings between the RDC leads were seen as helpful, although they can be difficult to get to, and have been organised on an ad hoc basis to date. The perceived value lies in them providing a forum for addressing common issues and creating opportunities to share learning. The potential duplication of such a network with the role of the EbE group was raised.

Other service users and carers employed by NIMHE

There are other service users and carers whose employment status is not as clear-cut. These are people who regularly chair meetings and provide a dedicated input to the programmes on a regular basis. Issues in relation to the obligations of NIMHE in the context of the European Working Time directive were raised. There was an indication from a small number that they would like to be more formally employed by NIMHE.

The issue of support was raised, particularly for those involved in chairing either at Board level, an Advisory or Reference group. This would seem to be useful and attention could be paid to the development of this group in particular.

Regional Networks

“These networks mean that NIMHE can be influenced from the ground up, which is where the real people are to be found”.

Networks were seen as being central to involving people in NIMHE. In some areas the networks of service users and carers predated NIMHE and were developed on a regional basis as a consequence of earlier development activity e.g. West Midlands and the North West. All the RDCs have developed (or are in the process of) developing databases and this was seen as an essential first step in developing involvement. The size of the regions and their geography clearly affect how these networks can operate. For instance in the South West the area covered stretches from Land's End to Gloucester and incorporates large rural areas. The viability therefore of regular meetings is questionable and other methods of involving people have been developed. The geographical allocation of workers, service user and carer leads and others was identified as facilitating involvement, particularly those in rural areas. Regional LIT networks for service users and carers were also identified as helpful mechanisms.

The difficulties of facilitating networks with the bureaucracy that seems to have developed around at least one network were referred to as being frustrating and unhelpful.

Payment for involvement

All of the RDCs reimburse expenses and pay a fee for involvement. Four copies of payments policies were sent and there are differences in what is covered, for example whether or not childcare costs will be covered. Expenditure on expense ranges from £4,000 to £40,000 for the year 2003-2004 across the RDCs. This may reflect differences in the geography of the regions, the public transport infrastructure (e.g. Freedom passes in London enabling anyone over 60 or with a disability to travel free), the organisation of meetings and the extent of involvement. It is not clear what the ratio between service user and carer expenses is as this information did not tend to be disaggregated. Although it is clear that prompt payment is valued, service users, in particular, raised concerns about jeopardising welfare benefits as a result of receiving this income. The issues of potential obligations under employment law were also raised by NIMHE.

Embedding service user and carer involvement across programmes

In general the feeling that service users, and carers, are on the edge of involvement was particularly expressed by the RDC leads for service user involvement. They conveyed a sense that service user and carer issues were not a priority whilst recognising that RDCs had a potentially overwhelming agenda. They referred to colleagues understanding at an intellectual level that service users and carers needed to be involved but not translating this into action, for

example service users were often not involved at the beginning of programmes but were typically an ‘add on’. Programme leads differed, possibly reflecting the nature of their programmes and it would appear that service users and carers are becoming more involved in some types of programme (e.g. social inclusion) than others (e.g. community teams). It may also be that the responsibility for service user and carer involvement within programmes is not entirely clear with programme leads viewing this as the role of the leads and vice versa. Strengthening involvement in programme areas is obviously one of the key ways in which service user and carer involvement can become more embedded into the work of the organisation.

3.6 Strengthening the involvement of carers

“We have to be seen as equal otherwise we are overridden and we waste our time over and over again”

Carers clearly feel unequal partners in NIMHE. They advocated that NIMHE needs to understand the distressing nature of caring and needs to take action on the issues that matter to carers. They felt that there was an underlying ambivalence about carers which resulted in their exclusion from decision-making at all levels.

There is a widespread recognition that NIMHE has not engaged with carers as well as with service users and as indicated earlier there are fewer resources invested in securing the involvement of carers. This needs to be reviewed and the involvement of carers strengthened.

3.7 Ensuring diversity

“Look at where these groups are and go and talk to them about NIMHE”

“Let’s avoid holding big events in City Centre hotels.”

“Someone to come and talk to us directly”

“Address institutional racism”

The key issue for all of the different groups was that NIMHE becomes skilled in listening to and committed to involving diverse groups. Individual reports from each of the different focus groups provide further detail and are available on request. It is clear that if different groups are going to become involved in NIMHE then its work has to be relevant and meaningful for those groups.

The importance of skilled listening without a predetermined agenda was highlighted repeatedly as it is clear that people will only want to become involved in NIMHE if they feel that it will take action on their agenda. There also needs to be an explicit recognition of the barriers to involvement that different groups face; for example the service users from black and minority ethnic communities described their experiences of racism encountered in mental health services, people diagnosed with a personality disorder raised the issue of stigmatisation by

some in the service user movement and the focus group for children and young people raised the importance of the organisational culture and its role in promoting (or inhibiting) the involvement of young people.

In addition there is a need for action to address the practical barriers that exist for diverse groups: language, childcare and other caring responsibilities, transport, isolation, no previous experience of participation, no access to IT were all highlighted.

Concerns had been raised during interviews about the difficulties of engaging with particular groups. However the process of engagement is key. The focus group targeted at black and minority ethnic communities was organised by two black members of the HASCAS team in partnership with the Race Equality lead for the West Midlands Regional Development Centre and the Service User lead. Between 230 and 250 people attended the focus group, including Vietnamese, Chinese, African Caribbean and South Asian communities. The knowledge of the Race Equality Lead combined with the strength of local networks, the availability of interpreters and the careful thought that was put into designing an event that would be attractive to different communities meant that it was well attended. The issue of engagement may therefore be something of a myth and what is required is time, effort and specific knowledge of the communities and minority groups concerned. Where this expertise is not available within NIMHE, it could work with or commission the voluntary sector to facilitate engagement on its behalf. The experience and track record of the voluntary sector in engaging with diverse groups needs to be recognised and this was raised at the focus groups for younger people, older people and black and minority ethnic communities.

The issue of information about NIMHE was central to the discussion about involving more diverse groups. All the focus groups called for clear and relevant information about NIMHE which makes the purpose of involvement clear. It was evident that the current arrangements are not working for these groups. The development of programmes has the potential to address this. The Race Equality Programme has recruited a lead for each of the RDCs, supported by a national programme lead, and they will play a key role in focusing on and engaging with these communities.

The methods that NIMHE uses to engage people need to be flexible and creative, for example, the use of text messages for younger people, cartoons, drop-ins. Postal and internet methods for consultation were suggested for those in rural areas although the limitations, in relation to accessibility, of these methods were also recognised.

There was a strong message that NIMHE needs to find ways of reaching out to these groups and not rely on people attending existing meetings. The potential for other service users or carers to act as a bridge to others to share information and encourage involvement was suggested.

However the overarching message to NIMHE was that there has to be visible evidence of the equality of opportunity in the way that NIMHE is organised and

staffed. There was a strong sense that the recruitment process both to NIMHE posts and to positions such as Fellow and Champion roles has been far from transparent.

3.8 Strengthening service user and carer at a local level

Involvement in NIMHE, either at a national or regional level is dependent on the existence of viable service user and carer groups at a local level. The work of Wallcraft (2003) is particularly helpful in this respect. From a national survey of service user groups Wallcraft found that most groups had fewer than 50 members, many had been set up as recently as five years ago and three quarters receive some funding (mainly between £20,000 and £40,000) for which they have to apply each year.

This has implications, particularly for commissioners, Primary Care Trusts and Local Authorities, in ensuring that there is investment in developing and sustaining service user and carer groups at this local level. Commissioners also need to ensure that sufficient consideration is given to user and carer involvement in their commissioning function and also in what they are commissioning from specialist mental health trusts and other organisations. NIMHE needs to work with PCTs, Local Authorities and Strategic Health Authorities (SHAs) to facilitate this.

Capacity building was identified as a key way to develop and strengthen user and carer involvement at a local level and this will help NIMHE move to a position where the development is happening “bottom up”. NIMHE therefore needs to pay sufficient attention to developments at a local level and its role in strengthening and facilitating this across programme areas, ensuring that local agendas are reflected in the work of the regional development centre and that the roles of user and carer leads are appropriately focused.

3.9 Strengthening service user and carer involvement in NIMHE

Vision

“It should not be about fitting service users and carers into NIMHE”

“I would like to see a Recovery of NIMHE whereby NIMHE begins to lead the way in firstly identifying the distribution of wealth within mental illness services (i.e. near zero spend on recovery/user governed organisations) and a shift towards a commissioning process where users and carers are not just involved but empowered with the tools to “drive their own car”

There was a consensus that people would like to see service user and carer involvement systematically embedded in NIMHE. For service users and carers this means leading, influencing and participating both in NIMHE's work

programmes and the governance arrangements for NIMHE and in developing the organisation and training its staff. This included the following:

- Clearly agreed purpose for the involvement of service users and carers
- Membership of and influence on decision-making at Board level at a regional and national level and other mechanisms to address governance in NIMHE
- Recruitment of service users and carers into a range of posts in NIMHE including service users in senior posts
- Service users and carers involved as a matter of routine and at the start of programmes and the process for other areas of work
- Involvement well resourced and supported
- Monitoring involvement by service users and carers to further strengthen it

Clarity of purpose

People need to know what the purpose of their involvement is and what difference it will make. People get involved for different reasons:

- To be listened to and use personal experience to bring about change in the way services are commissioned and delivered to improve the experience for other people
- To improve the civil status of people experiencing mental distress through tackling stigma, promoting recovery and redefining the relationship with services
- To support involvement beyond NIMHE
- To be involved to get information and be kept up to date
- To influence the work of NIMHE and its work programme
- To inform policy developments

There appeared to be a difference in emphasis between carers and service users in relation to involvement. Carers want to be listened to, to count and to influence the experience of services to improve them. They also want information and to be kept up to date about what is happening. Service users want these things too. However their agenda often tended to be more radical and many of those who took part in this review wanted to see changes in the civil status of people experiencing mental health problems as evidenced by a shift in the balance of power and responsibility from professionals to service users.

The way in which service user and carer influence decision-making within NIMHE needs to be clear. There is a shared agreement amongst NIMHE's staff, service users and carers that involvement needs to be strengthened so that service users and carers are involved in setting the agenda and influencing decision-making particularly at an executive level in order to shape what NIMHE does.

The importance of involvement being negotiated was emphasised during consultation and the need for NIMHE to be clear, honest and realistic about involvement and its limitations.

Information

“People need information on what NIMHE is, the specific opportunities to get involved, the purpose of being involved, what their role and responsibilities will be, any previous experience or skills needed in order to fulfil a particular role, what training will be given, what support they can expect, what payment will be made to them, how much time they need to commit, what is hoped their involvement will achieve and a complaints procedure.

Clear information about NIMHE, its purpose and the aim of service user and carer involvement is needed. Many of those who came to the Focus Groups had not heard of NIMHE or were unclear as to its role. The importance of straightforward information available in different formats was repeatedly emphasised. The importance of reaching out to broader groups of people and using existing networks to do this was also stressed. Information about how service user and carer involvement has made a difference to NIMHE is also needed if people are going to be persuaded to commit their time and energy to NIMHE. The value of service user- and/or carer-led initiatives is a recurrent theme across all of NIMHE's activities and in relation to information it was suggested that a book or newsletter written by service users and carers reflecting a range of achievements as a result of their involvement would be helpful for those considering getting involved.

Organisational culture

“NIMHE could set a goal of employing a minimum of 20% of people with lived experience.”

“Attitudes, attitudes, attitudes - need to be in the value base and through the organisation like letters on a stick of rock”.

Whilst many people identified practical steps that can be taken to strengthen service user and carer involvement in NIMHE, the environment within which these are introduced was seen as equally important. The employment of service users and carers by NIMHE and the training of all NIMHE staff by service users and carers were most frequently mentioned as measures which would help shape a culture within which involvement could flourish. In addition it was suggested that:

- The approach to involvement should set out to be inclusive aiming to include a diverse range of people and views and starting with the views, interests and concerns of service users and carers
- The time and investment in support that positive involvement takes needs to be acknowledged
- All programmes of work should involve service users and carers

- Senior staff need to demonstrate their support for service user and carer involvement and responsibilities for involvement should be part of core roles for Directors and programme leads
- There needs to be transparency in the way NIMHE works and the processes by which people can influence NIMHE and receive feedback need to be clear
- NIMHE needs to find out if, and take steps to ensure that, people are enjoying their involvement with NIMHE, finding it meaningful and have the support they need to continue to be involved

Involvement as a process of development

“Effective involvement often follows effective support or intervention. Only when some of the stress of the experience of mental distress or caring is relieved, can further involvement become possible. Ground-level workers should be found to champion involvement. Involvement may be linked to personal recovery, self-development and social inclusion”.

“Many carers and service users will be most interested in local, concrete and practical involvement. National and particularly regional involvement will follow from there.”

“Recovery is truly about people taking control of their lives, about self agency”

The approach to involvement as a developmental process was emphasised particularly in the responses to the consultation document. An approach to involvement which is underpinned by the principles of recovery and social inclusion was advocated. For example a parallel was drawn between the recovery process and involvement as a process and journey of self-development. (see *Emerging Practices in Mental Health Recovery, NIMHE, 2004*).

This implies that each programme at its inception needs to identify the best way of involving service users and carers and that there need to be a broad range of ways of involving and engaging with service users and carers. There also need to be processes for induction and opportunities for training and capacity building in place as well as ongoing support.

Practical and emotional support

“Providing a system of emotional support is the most important thing”

Practical support to get involved was, however, most frequently identified and included:

- A single clear payment policy which supports prompt payment of expenses
- Process of induction, preparation and debriefing

- Capacity building e.g. IT training, leadership development particularly as people move through different levels and types of involvement
- Funding and developing local networks
- Administrative support
- Identified budgets and resources
- Feedback

Strengthening the capacity of service users and carers was identified as key to strengthening their involvement. In addition to training and development opportunities the following were identified:

- Clarifying the role
- Support to participate, for example advocacy, having a buddy
- Adequate preparation, briefing and debriefing
- Tailored support to those in formal roles, such as Chairs of Boards and service user or carer groups
- Mentoring

This support needs to be flexible and responsive to different needs people have at different times and include the facility for providing emotional support if necessary.

Capacity and resources

There was a call for the investment in NIMHE in terms of staffing and resources to support involvement to be strengthened. The role of programme leads in relation to service user and carer involvement needs to be strengthened so that it is part of everybody's job.

Structures and accountability

There was an agreement that there should be a clear relationship between local, regional and national levels of involvement. Service users and carers want their issues represented and want individuals to be accountable to them for providing feedback and information. It was suggested that an independent national forum of service users, and separately of carers, should be developed and that NIMHE should be accountable to this forum in some way.

This suggestion was developed and outlined in the consultation document proposing a structure for representation. The response to this was mixed. Some respondents strongly supported it whilst others thought that the emphasis and investment in establishing such a structure would detract from NIMHE going out, engaging with existing groups and strengthening involvement from the grass roots. However whilst there is clearly a need to strengthen the investment in local groups and to strengthen the involvement in these groups, there needs to be a way of connecting these groups to each other and to regional and national activity.

Broadening diversity

There was clear support for broadening the diversity of service users and carers involved in NIMHE. The importance of NIMHE going out to the different groups to where they are and developing a process appropriate for that particular group was stressed, for instance:

- NIMHE should work with the community development workers to reach out to BME communities
- NIMHE needs to work with and learn from voluntary organisations who have a track record in involving younger or older people and work with them to support the involvement of these groups in NIMHE
- Finding the best ways of engaging with communities and minority groups e.g. children and young people could be engaged via schools, youth organisations etc.
- More outreach to rural communities is needed using the local press and going out to community-based events
- The space for specific agendas needs to be created e.g. abuse and discrimination
- Gay and lesbian organisations need to be contacted and to have information about NIMHE

It was proposed that steps are taken to ensure that minority groups are represented at Board level and on reference groups.

Developing involvement in NIMHE

The importance of an organisational commitment to developing service user and carer involvement in NIMHE was seen as the first step. There needs to be:

- Development of an independent service user (and carer) forum for NIMHE
- Culture of support with staff working to the same aim
- Critical mass of people to develop service user and carer involvement
- Acknowledgement and engagement with the difficulties

In addition the most commonly identified developments were:

- A communications strategy
- Single policy for payment
- A HR policy for the employment of service user and carer leads including salary scales, career development and reasonable adjustments
- Policy for involvement with NIMHE if you are not employed also including guidance on reasonable adjustments
- Appointment of service users and carers to the executive bodies within NIMHE at both a national and regional level
- Staff development to ensure that all staff have positive attitudes about the abilities of service users and carers and understand the factors that lead to effective involvement and the benefits.

Further clarifying the relationship between NIMHE and other organisations at a national level, such as the Health Care Commission and CPPI, and local organisations, could help strengthen involvement.

Summary

- NIMHE is a relatively young organisation and is developing a range of ways that service users and carers can become involved. There are examples both at a national and a regional level of the positive efforts that have been made.
- The overall assessment of service user and carer involvement suggests that they have little influence over NIMHE, on setting the agenda or making decisions. The majority of people in this review would like to see that change.
- Some community and minority groups experience additional barriers to involvement and the issues for black and minority ethnic communities, older people, younger people, people in primary care, those in rural communities, people with a diagnosis of personality disorder, gay, lesbians and bisexuals are were highlighted during the review.
- Service users are better involved than carers.
- At a national level service user and carer can be involved in national programmes including research. There is a national service user and carer group- the Experts by Experience group but its purpose is unclear and it is not well resourced. It does not have a formal link to decision-making (executive) bodies.
- Involvement at a regional level in the eight development centres is more positively evaluated and there is significant investment in supporting this. There are issues about the role of the service user and carer leads, their position within the development centres, their capacity and variations in what they are paid across the development centres. The extent of service user and carer involvement in regional programmes needs to be strengthened.
- NIMHE will need to work differently if it is going to involve a greater degree of diversity amongst service user and carer. This will involve going out to where people are, developing different ways of working and addressing the barriers which restrict involvement.
- Service user and carer and staff working for NIMHE want to see service user and carer involvement strengthened.
- For NIMHE to strengthen service user and carer involvement it needs to be clear about the purpose of being involved. This needs to be supported by straightforward accessible information and transparent and clear processes for recruitment, induction and training. NIMHE also needs to ensure that there is the additional practical support to get involved, as needed. It should develop a mechanism to ensure that local groups are connected to regional groups and are represented at a national level so they can influence and shape the agenda.
- The first step is to ensure that there is the organisational commitment to do so; this means a clear and explicit commitment to involving service user and carer in setting the agenda and in decision-making.

Chapter 4 Proposed framework for service user and carer involvement in NIMHE

*"I can liken NIMHE as body:
The skeleton is the framework,
The muscles are the users and carers.
We need to find the different exercises
To flex the different muscles,
Whilst careful not to break the bones;
And I think the decision making is best done
By a good heart that is considerate and in touch with the
body"*

This chapter outlines a framework for involvement. It was developed from the findings from the project with input from the Reference Group. Comments from the consultation process have enabled it to be further refined.

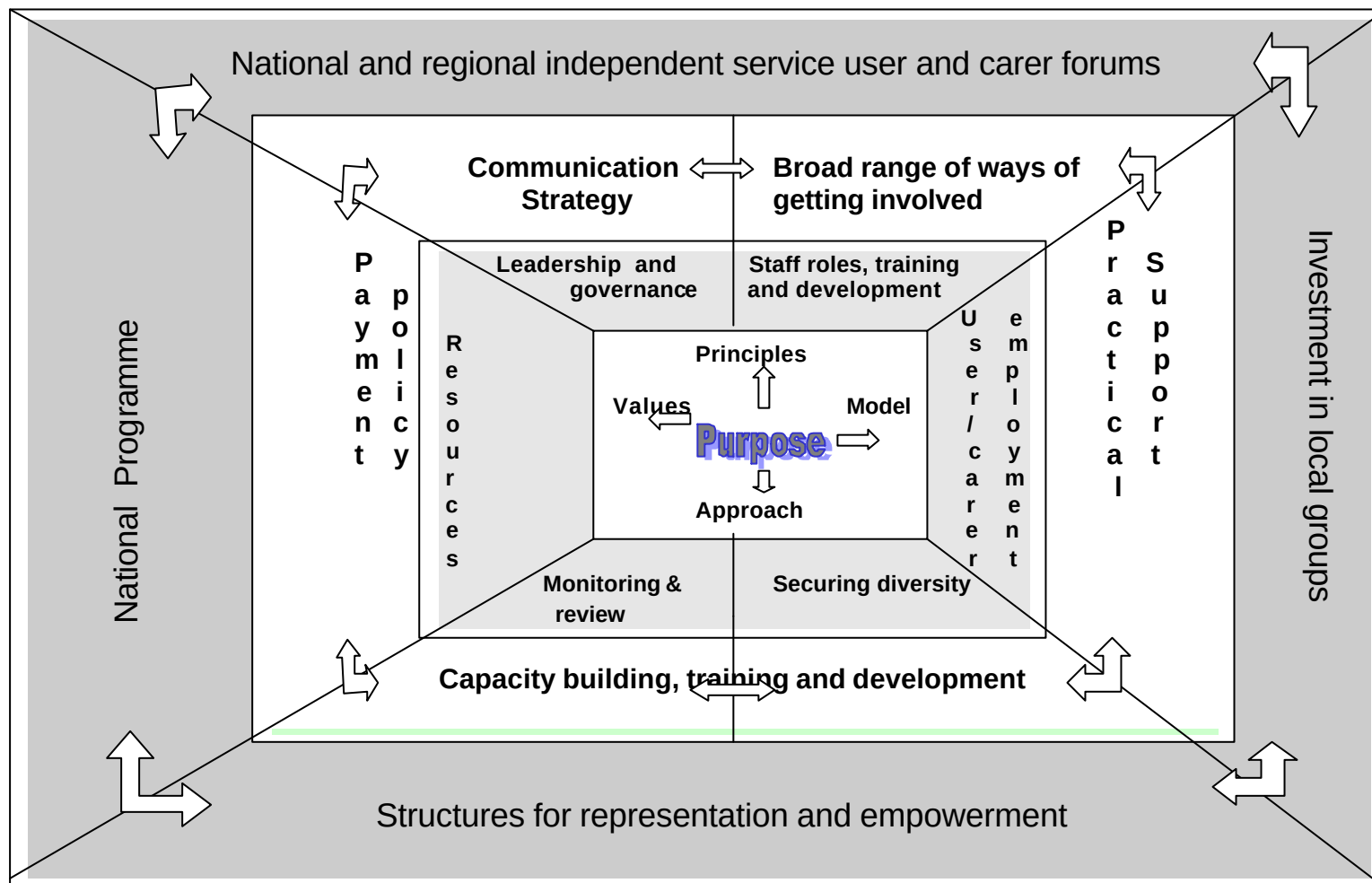
NIMHE, from its stated policy, views service user and carer involvement as integral to its primary task of improving the quality of life of people, of all ages, experiencing mental distress. This framework therefore identifies the ways in which service user and carer involvement can become embedded within NIMHE as an organisational routine that informs what NIMHE does and how.

This framework is just that. It aims to provide a starting point for the important detail to be worked out in a process of negotiation between service users, carers and NIMHE in individual programmes and development centres. It is this dynamic process, changing over time as the experience and learning of those involved grows, which is vital. It has to be underpinned by a commitment to an inclusive process which starts with the views, needs, interests and concerns of service users and carers and "grows involvement, expanding and deepening in an iterative fashion" (Godfrey et al, 2003).

There are four essential layers to this framework which are depicted in Figure 1. The first two levels provide a basis for the next two levels which outline practical steps to translate this commitment into practice. Without the foundation provided by these first two levels involvement is likely to be "*devoid of meaning*", "*an empty ritual of participation*" and "*tokenistic*". The levels are:

- Approach: this includes clarity of purpose supported by underlying principles, values and model of mental distress made tangible in the process of involvement
- Organisational culture: the environment which is needed for involvement to flourish
- Support mechanisms: includes policies, practical measures and a range of methods for strengthening involvement
- Structures for representation and empowerment: to provide a way that service users' and carers' issues get onto the agenda and their views influence NIMHE's decision-making at a local and national level.

Figure 1: A framework for involvement



4.1 Approach to involvement

Clarity of purpose

The first level which is at the heart of effective service user and carer involvement is being clear about the reasons for involvement (i.e. the purpose of involvement) and the approach to involvement which is being adopted (i.e. the underpinning principles, values, model of mental distress and the assumptions which underpin the process of involvement).

At the centre of this framework therefore is clarity of purpose about involving service users and carers. This was highlighted both as an issue of concern for people who participated in the review and also emerged clearly from the literature as one of the key factors which facilitates meaningful involvement. In Chapter 2, a distinction was also drawn between involvement fulfilling the needs of the organisation, where the organisation sets the agenda and defines what and how service users and carers can be involved, and a more democratic approach which is concerned with people having more say in agencies, organisations and institutions which impact upon them and being able to exert more control over their lives. This approach is “explicitly political”, highlights issues of power and is concerned with the redistribution of power and of promoting the self-determination and inclusion of people experiencing mental distress. “The concern is with bringing about direct changes in people’s lives through collective as well as individual action.”⁶

If involvement is to be strengthened and address the feelings of powerlessness and frustration which many service users and carers expressed then the purpose of involvement needs to be explicitly democratic in its approach.

On this basis, the purpose of involving service users and carers in NIMHE is therefore:

To increase the influence of service users and carers on the approach to policy and practice in relation to people experiencing mental distress. This has three elements. Firstly to improve the civil status of people experiencing mental distress. Secondly to improve the access to mainstream opportunities for people experiencing mental distress. Thirdly to influence the design, development and improvement of mental health services and the quality of life of people who use them and that of their carers. These elements involve influencing the development of NIMHE’s work plan and facilitating involvement in planning, commissioning and monitoring development and governance of local services through:

- Listening to, utilising and valuing the experience of service users and carers to bring about change

⁶ Beresford P. (2002). User Involvement in Research and Evaluation: Liberation or Regulation? *Social Policy and Society* 1:2, 95-105.

- Providing opportunities for the development of service user- and carer-led initiatives
- Enabling carers and service users to work within wider settings to promote mental health, recovery and social inclusion for themselves and others
- Linking individual and local experiences to inform the bigger picture and the development of mental health policy

This implies:

- Influencing decision-making at all levels within NIMHE including the executive level and across all programmes
- Service users and carers in leadership roles
- Contributing to the development of NIMHE's strategy, policy and work programmes at a national and regional level
- Facilitating the involvement of service users and carers in local services
- The development of service standards by service users and carers as a guide for development and as a basis for reviewing the impact of the action taken

These aims provide a basis for more specific ones to be developed by individual areas of activity, e.g. programmes, in a process which involves service users and carers. They will need to be translated into meaningful outcomes which can be monitored.

This purpose needs to be supported by a set of underpinning principles, values, a social model of disability and an approach to involvement which is developmental, aiming to build capacity and provide a route to other opportunities.

Principles

NIMHE recognises that service user and carer involvement is integral to its work and aims to place service users and carers at the centre of everything it does. Its approach to involvement will be:

- **Inclusive:** NIMHE will seek to actively engage with individuals and communities which reflect diversity in terms of age, gender, disability, ethnicity and sexuality.
- **The purpose of involvement will be clear:** this will involve being transparent and honest about why, how and what of involvement including being clear about the roles and responsibilities this implies.
- **Developed from the grassroots upwards:** starting with the agenda of service users and carers through engagement with local groups
- **Flexible:** so that the most appropriate way of involving people is found for programmes of work and in the different regions.
- **Developmental and meaningful:** the process of involvement will aim to build and develop their capacity both for the individual and in relation to supporting involvement external to NIMHE. This process will be

underpinned by the principles of equality, recovery and social inclusion i.e. everyone has the right to a meaningful and valued life.

- **Underpinned by a commitment to shift the balance of responsibility from professionals to service users and carers** so that service users and carers clearly influence decision-making and their views are given at least equal weight. All parties need to recognise the commitment this will involve and their responsibilities to each other.
- **Aim to embed involvement within NIMHE** whilst recognising that an independent service user and carer voice is vital.
- **Recognise that service users and carers have a different perspective and different issues as well as many shared concerns.**
- **Ensure involvement is well supported** through induction, appropriate support and debriefing. Training will be available and people will be reimbursed for their time and expenses incurred.
- **Sensitive to the nature of mental distress and the caring role**, and be anti-oppressive and anti-discriminatory. People must be able to participate safely, not be subject to intimidation and should have recourse to action if this happens.
- The complex nature of NIMHE needs to be recognised and there needs to be **a commitment to and preparedness to learn** and share lessons about involvement; both what is working well and what is difficult across the organisation.

Values

On the face of it, principles and values may appear to be one and the same. Principles are specific, they provide a foundation and a reference point and the ones developed above apply specifically to service user and carer involvement.

Values are more general and the values which need to underpin service user and carer involvement are a belief in self-determination and the need to promote choice and increase the control that people have over their lives. These values will need to permeate other aspects of NIMHE's work and are evident in work related to social inclusion, recovery and the implementation of initiatives such as direct payments. NIMHE has a work programme on values and it will be important that this is connected to work to strengthen involvement.

Model

Underpinning involvement with a social model of disability is likely to strengthen involvement because it establishes as its starting point that everyone is equal. It focuses attention on society which erects barriers that prevent disabled people participating and restricts their opportunities. It is a model which has been developed and advocated by disabled people and in mental health is clearly consistent with NIMHE's current emphasis on social inclusion and recovery.

"In the broadest sense the social model of disability is about nothing more complicated than a clear focus on the economic, environmental

and cultural barriers encountered by people who are viewed by others as having some form of impairment - whether physical, sensory or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media - films, television and newspapers”.

British Council of Disabled People
See www.bcdop.org.uk

The social model of disability does not ignore questions and concerns relating to disability and/or the importance of medical and therapeutic treatments. A social model acknowledges that in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of appropriate help. Implicit in this model is a commitment to human rights and tackling discrimination associated with mental health problems.

Involvement as a process of development

The principles, values and model translate into an approach to involvement which views involvement as a process of self-development. Involvement which aims to build capacity and have the potential to open up employment opportunities and career pathways was stressed both during the review and consultation process. Furthermore the opportunities that have been developed within NIMHE, particularly leadership development for service users and carers, are highly valued. This approach to involvement is consistent with NIMHE’s stated aim of “*providing a gateway to learning and development, offering new opportunities to share experiences and one place to find information*”⁷.

4.2 Organisational Culture

“Rooting involvement in agency policy and practice requires a shift in organisational culture from doing things for people, to doing things with them. To make such a shift effective and not simply the stuff of empty rhetoric requires leadership, commitment and enthusiasm from the top, sustained through the provision of support and training for staff at all levels and developed through a culture of openness and valuing of different perspectives. Fundamental to the process is a consideration of the kinds of capacities and skills that may need to be fostered within the agency and among service users and an investment of resources (both staff time and money) to effect change.

Godfrey et al. 2004

⁷ Recovery and Change – Mental health into the mainstream: Annual Report and Strategic Plan 2003/02-2005/06

The second level is the organisational culture of NIMHE, its regional development centres and programmes and this is as important as developing practical measures and structures in enabling involvement to flourish. Middleton et al (2004) have developed a typology for service characteristics based on an analysis of involvement in mental health services. This has been adapted to fit the current context and to take account of the data collected as part of the review. These different types of organisational culture are contrasted in Boxes 4 and 5 and provide a basis for a self-assessment tool for programmes and development centres to assess the culture in which they are aiming to 'grow' involvement.

Box 4: Positive organisational climate: Collaborative and enabling

- Clarity of organisational aims and purpose of involvement
- Diversity in the staff team and leadership with service users and carers in senior positions
- Service users and carers represented on management/executive boards with regular time allowed for discussion on user- and carer-driven issues
- Information strategy to connect service user and carer groups which uses a variety of methods and is available in different formats
- User- and carer-focused goals built into staff job descriptions and objectives
- Staff training and development by service users and carers
- Employment of service users and carers who are well supported by the organisation, have attention paid to their personal development and to appropriate adjustments
- Role of user and carer leads to facilitate the involvement of service users and carers within and beyond NIMHE
- Mapping service users and carers groups locally
- Resources available to support involvement
- Induction, training, practical and emotional support available to facilitate involvement
- Process of review and reflection on the quality and outcomes from involvement including ways of illustrating how service users and carers views have been acted upon

Box 5: Negative organisational culture: Rigid and unresponsive

- Absence of service user and carer representation on exec group/management team and/or no space on the agenda for service user and carer issues
- Service user and carer issues frequently deferred in team meetings
- Service user and carer leads feel unsupported, supervision imposed or virtually non-existent and have no access to resources to facilitate involvement
- Inequities in pay between service user and carer leads and others in similar roles and/or no consideration given to appropriate adjustments or other evidence of discrimination
- Service user and carer leads called on to represent user and carer views
- Staff actively opposed to involvement
- No connection and investment in local groups
- No process for review and reflection on involvement

The elements which will facilitate the development of a positive organisational culture identified by this review are:

Leadership and governance

The focus on service user and carer involvement and the leadership provided by staff employed by NIMHE to progress this agenda, at both regional and national level has clearly been helpful. This leadership and ensuring that service users and carers are involved in governance can be strengthened in a number of ways.

1. Appointing a national director for involvement

The response to the consultation document supported the proposal of the creation of a national post at director level. However it was suggested that there would be advantages to this being a single post rather than 2 separate ones, one for service users and one for carers. There was also the suggestion that this post could be located outside of NIMHE within other Department of Health structures for public involvement. Further work on the options needs to be done.

The director would have overall responsibility for coordinating and strengthening service user and carer involvement and linking with other organisations and forming new partnerships to achieve the increased

involvement of service users and carers. The role would be a facilitative one to ensure a focus on involvement and to support other programme leads in embedding it within their programmes and within the regional development centres as well as providing leadership for the proposed national programme which is outlined in the next section.

The post would need to be adequately supported in terms of having an identified budget and administrative support.

2. Clear responsibilities for involvement for RDC Directors and national programme leads

In addition to this the responsibilities of RDC Directors and national programme leads for service user and carer involvement within their area of activity should be clear. This would include the development of detailed and costed plans for service user and carer involvement.

3. Service user and carer involvement in governance

Service users and carers should be involved in the governance arrangements for NIMHE. Where not already established, service users and carers should be involved at Board level for the regional development centres. There should be a minimum of two service users and two carers. Regional development centres should retain the flexibility to recruit from local service user and carer networks in the way which best fits the local situation. It may well be helpful to have a service user and carer stakeholder group, if not established, to populate this structure.

Ideally one of these post holders would co-chair the Board. These individuals however should be connected to these local networks and therefore able to represent, at the Board level, the collective perspective of these local networks. These roles should be well supported. Their role in relation to those who are not currently well represented or heard will need to be scoped and defined. They could for instance be involved in facilitating an annual service user and carer evaluation of the RDC's work.

Staff roles, training and development

If facilitating involvement is part of the ethos then responsibilities for service user and carer involvement will be outlined in job descriptions for all NIMHE staff. This will be supported by training, in response to identified needs, which should be delivered by service users and carers. In addition there needs to be training on diversity including equality, race, gender and disability.

Employment of service users and carers

The employment of service users and carers is a critical factor in facilitating a supportive climate. There are two aspects to this; employment of appropriately qualified service users and carers in any of NIMHE roles and employing service users and carers in specific roles to develop involvement. The employment of

service users and carers will be facilitated by a human resources policy that conforms with the Disability Discrimination Act and builds on current best practice. This is an issue for the host organisations to review current policies and practice. For service users and carers in development posts there needs to be attention to their personal and career development so that there is the opportunity to move into other roles within and beyond NIMHE.

Securing Diversity

There are six key areas that need to be considered whatever the particular minority group or community that is being considered. These are:

1. Organisational development so that people from a diverse range of backgrounds are employed at all levels within NIMHE. Ensuring that there is effective monitoring in place to establish whether this is happening and that there are mechanisms for addressing this.
2. Organisational and staff attitudes to involving a diverse range of people. This means being willing, and having the resources to take the time and effort to bring people together to seek their views and work out how best to involve them. It also means being alert to the ways in which discrimination can be institutionalised. The need for training for staff and for service users and carers in diversity has already been highlighted.
3. Development of employed staff so that there is a good understanding of diversity. This will mean working in partnership with the voluntary sector and community groups to develop this understanding.
4. Engaging with the specific communities and networks to clarify how people might get involved, what will be the best way of involving them and what support or resources they will need to become involved and what practical issues need to be addressed. This needs to look at how NIMHE might need to change so that there is a range of flexible and creative ways for people to become involved.
5. Clearly identifying the practical issues which need to be addressed for people from different backgrounds. A clear understanding of the barriers to their involvement, the pitfalls and ways of overcoming these is needed.
6. Working imaginatively through organising open events, in a range of venues, in different formats, working with independent advocacy services or frontline workers, and community engagement workers, to engage with people.

The programmes are a central strand for NIMHE in securing diversity as they focus on particular groups (e.g. children and adolescents, older people, acute in-patient care, primary care, race equality, gender etc.). These programmes will need to develop positive plans for how they are going to achieve diversity in their involvement. There is no better source of advice than from these groups themselves. There will be much to be gained from working in partnership with others and there is extensive experience in the voluntary sector which could be commissioned.

Monitoring and review

“Review involvement regularly to see how it is going for those involved, whether involvement opportunities are being advertised and accessed by enough people, who is not getting involved and why. Need to review whether what is said happened on paper happens in practice. Need to look at people’s experience of involvement and the impact it’s had for future improvement. Need qualitative data from participants rather than statistics and the opportunity to say what they want”.

Both the processes and outcomes of involving service users and carers in NIMHE need to be reviewed and appraised on a regular basis to ensure that the original aims are being met. It has been proposed that national service user and carer forums could take on this function at a national level and regional forums at that level could carry out this work. However it will be important to ensure that such a process involves listening directly to service users and carers about their experiences and reviewing what is happening in practice. It will need to be a two-way process to see how the process is working from the perspective of service users, carers and NIMHE. The development of standards by service users and carers which could be used to review involvement in regional development centres and programmes would be useful.

Resources

Service user and carer involvement clearly needs to be resourced with identified budgets for programmes and regional development centres.

4.3 Support to get involved

This third level of the framework identifies the support which needs to be available to facilitate access and support involvement and again builds on the key themes which emerged during the review and the available literature.

Information and communication strategy

There needs to be accessible information which enables people to make an informed choice about whether or not to become involved with NIMHE. People will have different reasons for getting involved and involvement in an organisation other than NIMHE might better fit their interests. For example if people are keen to see improvements in how services work in their area they might have more impact if they got involved in the local service user group or Patient and Public Involvement Forum. People therefore need information about the different opportunities for involvement so that they can choose how best to invest their time and energies. The Route Maps developed by Allies for Change (SDC 2001) provide a useful starting point for thinking about this. Appendix 3 provides an illustration of how this might be developed.

The information people need about involvement in NIMHE include the purpose of involvement, the different ways of getting involved in NIMHE at a regional level, at a national level and in programmes and what impact service users and carers can expect their involvement to have.

There is also a need for agreed mechanisms for communication and providing feedback to service users and carers at different levels of involvement. These should be simple and easy to access. There should be opportunities for different groups to share with each other their experiences of involvement such as younger people who will become older, learning from older people about their experiences and outcomes of involvement (Carter & Beresford, 2003; SDC, 2001).

Broad range of ways of getting involved

The responsibility for engaging with service users and carers should lie with NIMHE. This means that NIMHE has to be proactive in its approach, reaching out to diverse groups of individuals and communities, using different methods to engage people.

Service users and carers should have different ways of becoming involved in NIMHE as a result of their desire to use their experience. They could become involved in NIMHE in training and developing the capacity of staff (how well NIMHE understands service user and carer issues and involvement), in programmes to reshape provision and support development including research (what NIMHE focuses on and how) and in the governance arrangements for NIMHE (what NIMHE decides). There needs to be a broad range of methods for involving people from one-off informal events (e.g. open space events, conferences, focus groups etc.), to a more sustained involvement in a programme of work (as a team member, providing expert input, as a member of a steering group etc.) to becoming actively involved in the governance arrangements (as a member of a programme board, regional development centre board etc.).

Whatever way people choose there needs to be an emphasis on building capacity and ensuring that involvement is meaningful. This means providing people with an introduction to NIMHE through information and an induction or welcome process. It means being clear about what support people need to participate fully, identifying how they want to become involved and reviewing how their involvement is working out. An over-reliance on formal meetings needs to be avoided; engaging with local groups, going to where service users and carers meet, mapping local community organisations, informal social events, holding more formal meetings at the end of a more open inclusive and informal meeting and finding ways of *"tapping into the day-to-day lived experience"* of service users were repeatedly emphasised during the review and are important strategies for broadening the diversity of the groups involved.

Payment policy

Reimbursing people for their expenses which include travel, childcare and cover for other caring responsibilities as well as making a nominal payment in recognition of people's contribution will facilitate involvement, has been repeatedly emphasised during the review. There needs to be a single clear payment policy which supports prompt payment of expenses and is agreed with the Department for Work and Pensions (DWP). This should enable the fast tracking expenses for service users and carers with the minimum of bureaucracy.

Practical and emotional support

People need to find it easy to participate and there is a wealth of information about the measures which need to be taken. This is summarised in a working paper for the review which provided a basis for Chapter 2. There needs to be a good understanding of the particular barriers which inhibit involvement for different groups (see Chapter 2 for a summary of some of these) and action taken to address specific issues. In general the support which should be available includes:

- “Welcome process” of induction, preparation and debriefing
- Meeting in accessible venues (time, place and familiarity)
- Careful thought given to style of engagement (informal, accessible)
- Additional support with communication (interpreters, loop systems, visual aids)
- Administrative support
- Advocates or buddies
- Peer support
- Staff with responsibilities to provide support or access to appropriate support
- Identified budgets
- Clear accessible information
- Payment policy
- Guidelines for those coordinating activity/chairing groups which outline responsibilities including induction and debriefing, information about safe participation supported by training for all
- Training for service users and carers (see below)

Capacity Building

A key role for NIMHE is to support and promote people's capacity to contribute, to increase the range and depth of their involvement for people within NIMHE and beyond NIMHE. Therefore building capacity is key to strengthening involvement and includes:

- Paying specific attention to training and development needs as individual service users and carers move from involvement at a local level to representing a collective agenda at a regional and/or national level
- Leadership and personal development programmes

- Shadowing, mentoring and coaching
- Specific training initiatives developed in response to identified needs, e.g. IT training, working with the media, running effective meetings etc.
- Developing specific skills e.g. in-service development, research or writing for publication
- Linking more active people with less active people to develop confidence
- A career pathway for people employed in service user and carer roles within NIMHE

4.4 Structures

The fourth level describes a number of structures which are designed to ensure focus and leadership and to ensure that the concerns and views of service users and carers at a grassroots level are informing and shaping the work of the regional development centres, the NIMHE programmes and the overall governance of NIMHE.

Local networks

Involvement of service users and carers in NIMHE is dependent on the existence of groups at a local level with which NIMHE can connect. There are a number of issues NIMHE needs to consider in relation to these groups:

- Ensuring that sustainable investment in service user and carer groups forms part of local commissioning strategies
- Identify positive commissioning practice
- Map local groups and identify gaps, consider the steps that could be taken to address these, for example working in partnership with the voluntary sector
- Finding ways of engaging service users and carers who are not members of formal groups
- Information networks which connect local service user and carer groups

If NIMHE is to strengthen involvement from the grassroots upwards, the ways of connecting with these groups will need to include going to their meetings, providing a mechanism for information flow between NIMHE and vice versa and exploring ways to ensure that the day-to-day experience of service users and carers is reflected.

Local groups are likely to be also connected to other organisations who may recruit from these groups to be involved in aspects of their work, for example PCTs, Mental Health Trusts, Patient and Public Involvement Forums and local Universities. NIMHE plays an important role in facilitating involvement in these groups and therefore needs to work in partnership with these organisations.

Independent regional and national service user forums

The existence of regional and national forums for service users and carers provides a means of networking, sharing information and a mechanism for

ensuring the views and concerns of members of local groups are aired and for addressing this agenda through formal links with NIMHE. There are regional groups of service users and carers in existence across NIMHE which are usually supported by the development worker from NIMHE. Their degree of independence from NIMHE may well vary and it is worth reviewing this with the groups concerned.

There is support, from the consultation responses, for establishing an independent forum for service users and an independent forum for carers. However it was also clear that as service users and carers share many concerns these groups will need to work together. The constitution of these groups needs to be developed by service users and carers. However their function could include:

- To act as steering group for a national service user and carer programme
- To act as a conduit for consultation and involvement in national activities
- To facilitate networking between service users and carers involved in NIMHE
- To bring together concerns identified at a local or regional level and identify how these issues could be addressed
- To identify good practice, for example researching what the voluntary sector does well
- To develop standards for monitoring service user and carer involvement in NIMHE
- To raise the profile and understanding of user and carer involvement
- To act as a resource for service users and carers involved in NIMHE's national programmes
- To produce high quality service user and carer publications
- To help develop leadership roles
- To link with external organisations e.g. SCIE (Social Care Institute for Excellence)

It is important that these groups are independent of NIMHE but have formal links into NIMHE at an Executive Level so that these groups can influence decision-making and ensure that service user and carer issues are on the national agenda. They need to support involvement at a regional level and local level and the next section suggests a way of ensuring that this can happen.

The different ways in which the development of such national forums could be managed are:

- NIMHE could establish these groups
- NIMHE could provide the coordinating and administrative function and commission an independent organisation(s) to develop these groups
- An independent organisation(s) could be commissioned to provide the coordination, recruitment and development of these groups.

The membership must ensure that the diversity of interests is well represented. This includes regional representation, appropriate age and gender balance, robust representation from BME communities and representation across the spectrum of need including people with a diagnosis of personality disorder and those using primary care.

In addition service users and carers who work for NIMHE, in development roles, also need a forum to express their views and to shape NIMHE's work in relation to involvement, based on their experience. This network will need to feed into the independent national forums.

The current EbE group could play a role in facilitating the development of these groups and it is important that this existing expertise is not lost but is strengthened.

Structures for representation and empowerment

To strengthen influence and ensure involvement in decision-making a representative structure was proposed and described in the consultation document. It is outlined in Appendix 4 and aimed to facilitate clarity about how service users and carers can influence decision-making within NIMHE. It proposes a structure for the relationship of service user involvement at a local level, at a regional level and at a national level and outlines a way in which local and regional interest can be represented at a national level on the NIMHE Executive.

Independent service user and carer groups, proposed in the previous section, are a key element of this structure and the membership could include regional representatives, representation from those in national programmes and representation from independent organisations. The regional representatives would need to ensure that issues are fed in from a local and regional level to a national level and vice versa.

Individuals from the national service user and carer groups would be nominated, by their peers, to sit on the NIMHE Executive and it is proposed that this group is co-chaired. It will be important that the NIMHE Executive includes functions in relation to service user and carer involvement specifically:

- Agreeing the national work programme for NIMHE including the balance of work in relation to service user and carer involvement
- Agreeing the annual budget for NIMHE, the programmes and the RDCs including for service user and carer involvement
- Agreeing and sponsoring action on a service user and carer defined agenda

This proposal to develop a representative structure met with a mixed reaction. From some there was clear support. For others there were reservations, asking for more detail and clarity on what this would look like. Finally for others, there

was a concern that the development of such structure would detract from facilitating involvement at a local level and that investment in this structure would be at the expense of local involvement.

This clearly needs further work and it is proposed that this is an early task for the national programme. The existence of a representative structure has been identified by a major review of the literature on service user involvement in change management as an important factor (see Crawford et al, 2003) and this was supported by this review which highlighted the need for clear mechanisms for communication and for service users and carers at a local level to be able to see their agenda reflected at national level with evidence that action was being taken on it. However given the reservations other models of influence should be considered with a costed option appraisal.

National programme

A national programme for service user and carer involvement would provide a mechanism for:

- Coordinating developments and create the opportunity to share good practice, progress action on areas of work identified by the local, regional and national service user and carer groups. For example each of the individual RDCs could therefore undertake activity in relation to an aspect of service user and carer involvement on behalf of the other RDCs. For example developing a single payments policy, developing a shared approach to capacity building, modelling different approaches to involving service users and carers from minority groups.
- Developing a corporate approach in terms of policies: single payment policy, human resource policies etc.
- Monitoring progress in relation to the strategic objectives
- Support involvement in regional development centres and NIMHE programmes through the development of a network of the service user, carer and programme leads. This network would meet on a regular basis to share good practice and provide peer support
- Support the development of service user and carer involvement in NIMHE's programmes through providing information and support. It should not become a substitute for ensuring that involvement is integral to these programmes
- Commission further work on involvement and innovative approaches to emerging issues
- Developing joint work with other national organisations, such as those within CSIP (see Chapter 5), Commission for Public and Patient and SCIE.

4.5 What would adopting this framework mean for NIMHE?

At a national level:

- Agreed purpose for the involvement of service users and carers
- Developing a corporate strategy for involvement
- Development of a national programme for service user and carer involvement
- Appointment of a national director of involvement
- Development of independent service user and carer groups with involvement in the governance arrangements for NIMHE
- Agreed mechanisms for ensuring service users and carers influence NIMHE's agenda and for providing feedback and clear communication to service users and carers at different levels of involvement
- A communication strategy which outlines how to provide clear information about NIMHE and how to get involved both in NIMHE and other organisations
- A single clear payment policy which supports prompt payment of expenses and is agreed with the Department for Work and Pensions (DWP)
- Development of policy for the employment of service users and carers by NIMHE and on a more casual basis in the context of current employment legislation and good employment practice
- Standards for the involvement within national programmes and at an RDC level as agreed by service users and carers
- Training and development of all NIMHE staff on involvement and engaging with a diverse range of service users and carers
- A shared approach to capacity building and leadership development for service users and carers in response to their identified needs and role
- Arrangements for monitoring how effectively service user and carer involvement is happening.

At a regional level

- Clear information about the RDC, the purpose of involvement and how to get involved
- Responsibilities for service user and carer involvement outlined in job descriptions for NIMHE staff including RDC directors
- Development of independent service user and carer groups with involvement in the governance arrangements for the regional development centre
- Developing a broad and flexible range of ways for service users and carers to get involved including reaching out to different groups and providing the necessary support to become involved

- Training and development of all NIMHE staff on engaging with service users and carers
- Capacity building and development opportunities for service users and carers
- Facilitating the development of and involvement in local networks and local organisations
- Identified budgets and resources
- Informal events to engage broader networks of service users and carers
- Feedback and monitoring mechanisms for service user and carer involvement

At a programme level

- Clear information about the programme, the purpose of involvement and how to get involved
- Responsibilities for service user and carer involvement outlined in job descriptions for programme leads
- Development of a reference group for the programme to support service user and carer involvement in the programme board
- Developing a broad and flexible range of ways for service users and carers to get involved including reaching out to different groups and informal events to engage broader networks of service user and carer
- Providing the necessary support to become involved
- Training and development of staff on engaging with service users and carers
- Capacity building and development opportunities for service users and carers involved in the programme
- Identified budgets and resources
- Feedback and monitoring mechanisms for user and carer involvement

Summary

- ***A framework is described which builds on the findings from the project.***
- ***The framework describes four levels which are:***
 - ***A clear purpose for involvement in NIMHE so that service users and carers know what they are getting involved in and why. It also means clarifying the approach to involvement which includes the underlying principles, values, social model of disability and the process of involvement.***
 - ***The organisational culture which will facilitate involvement and includes leadership, governance arrangements, staff roles, training, employing service users and carers, measures to secure diversity, monitoring and review and resources.***
 - ***The support that people need to get involved which will include an information and communication strategy, being flexible and having a broad range of ways people can get involved, single payment policy, practical and emotional support and capacity building, training and development.***
 - ***Structures for representation and accountability so that service user and carer issues are represented at all levels within NIMHE and influence the work that NIMHE does. This includes investment in local groups, developing independent service user and carer groups at both regional and national level and the development of a national programme to coordinate effort and disseminate good practice.***
- ***The implications of this model are identified for NIMHE at a national level, for regional development centres and for programmes***

Chapter 5 The Future

5.1 Implementing the Framework

NIMHE has made progress in involving service users and carers. This needs strengthening in seven critical ways:

1. To clarify the purpose of involvement.
2. To strengthen involvement through supporting involvement at a local level.
3. To sustain involvement through the strengthening of communication and support mechanisms and develop the capacity of those involved.
4. To broaden the diversity of service users and carers by strengthening the involvement in NIMHE programmes and regional development centres.
5. To ensure that service users and carers are involved in decision-making and executive functions of NIMHE at a regional and national level and within programmes.
6. To strengthen the service user and carer voice by developing independent service user and carer groups at a national level.
7. To focus and coordinate the effort in relation to service user and carer involvement through the development of national programmes with a national director of user and carer involvement.

This needs to be underpinned by an organisational commitment to making it happen.

If this framework is agreed a costed and timetabled implementation plan will need to be developed. This plan will need to map out the transitional arrangements for any groups, or individual, who will be affected by this development. It will also need to be refined in the light of the development of service user and carer involvement in the Care Services Improvement Partnership.

5.2 Other issues for consideration

This review has highlighted a number of areas where further work would be useful:

- To develop the information about good practice for involvement in relation to diverse groups
- To review models of influence and develop a costed option appraisal
- The involvement of service users and carers in commissioning work on behalf of NIMHE.

5.3 Issues in relation to NIMHE and CSIP

The Care Services Improvement Partnership (CSIP) is currently being developed as an initiative by the Department of Health, to bring together the work of a number of existing organisations and programmes in the field of social care. CSIP intends to bring together the work of seven existing organisations and work programmes⁸. The CSIP will focus on supporting services for children, people with a learning disability, mental health problem or physical disability and older people. The partnership is intended to provide greater coordination and coherence in the way the seven organisations work together across the statutory, independent and voluntary sectors, by providing a range of implementation, service development and support services. Key objectives of the CSIP are to improve learning and service development both within and across agencies, and to support the development of social care programmes which need effective partnership working.

Key principles of the CSIP are that it should be flexible and responsive to local needs, and it will work collaboratively with service users and other stakeholders to ensure future policy takes account of their views. The partnership will be part of the Prescription Pricing Authority and organised regionally through eight regions, configured around the existing NIMHE development centres. Work is underway to map out how the involvement of people from different care groups and their families will be secured.

This imminent change was seen as both an opportunity and a threat during the review. It has the potential to widen service user and carer involvement to include service users and carers from other groups (who may well not use these terms to define themselves) so that the involvement, particularly of children and younger people, older people and people with a learning disability and mental health problems is strengthened within NIMHE. Service users and carers from other groups are likely to have issues in common and this could strengthen policy development in relation to service user and carer involvement. However concerns were raised about the role of CSIP and whether its focus would be narrower than NIMHE's, focusing solely on service improvement, meaning that the potential for involvement might be more limited.

Concern was also expressed about the size of the agenda facing CSIP and the possibility that service user and carer involvement might get lost. The greatest risk is that these organisational changes, and potential changes in staffing, may

⁸ These organisations and programmes are:

- Change for Children
- Health & Social Care Change Agent Team
- Integrating Community Equipment Services
- Integrated Care Network
- The National CAMHS Support Service
- National Institute for Mental Health in England
- Valuing People Support Team

mean that there is a loss of momentum in implementing the changes identified in this report.

It is therefore vital that consideration is given to sustaining the current levels of involvement and to using the emergence of CSIP as an opportunity to further strengthen involvement.

Summary

- ***NIMHE needs to develop the detail for the proposals which have been outlined.***
- ***A clear and costed timetable for implementing the proposals needs to be developed to ensure that action to address the issues identified can be taken promptly.***
- ***NIMHE needs to provide clear feedback on this review to service users, carers and NIMHE staff and outline the steps that it intends to take.***
- ***NIMHE needs to ensure that service user and carer involvement is built into the Care Services Improvement Partnership and take steps to ensure that the motivation, momentum and expertise in relation to strengthening service user and carer involvement is safeguarded.***

Chapter 6 Recommendations

1. NIMHE needs to be clear about the purpose of service user and carer involvement.
2. NIMHE needs to decide whether or not to involve service users and carers as partners in decision-making.
3. NIMHE needs to identify areas of work where service users and carers lead and have overall control.
4. NIMHE should ensure it has a broad range of ways of engaging with a broad range of people experiencing mental distress, their families and carers, including going to where people meet, informal events and focused approaches to ascertaining service user and carer views.
5. A key focus for NIMHE should be enabling and supporting service users and carers to be involved in local groups. NIMHE needs to work with commissioners to support investment in the development of local mental health service user and carer groups.
6. NIMHE should establish a national user group and a national carer group, with appropriate and clear relationships to regional development centres and to local groups which enable the local agenda to be reflected at a national level. These national groups should be represented on the NIMHE Executive, the key decision-making group for NIMHE to ensure that NIMHE's work programme includes action on a service user- and carer- generated agenda. The NIMHE Executive will need to be reshaped to allow service user and carer representation on this group.
7. NIMHE should establish a programme for service user and carer involvement with a national lead at Director level. The role would be to facilitate work across NIMHE on the key issues identified and to coordinate the work of regional development centres. The post holder would also work with other organisations, within CSIP and the Department of Health, to develop a coherent approach across different care groups and different functions. The development of these roles will have implications for the current EbE Fellow and this role will need to be reviewed in the light of this.
8. The involvement of service users and carers across all NIMHE programmes needs to be strengthened. All programmes need to consider how to involve service users and carers at the start and all the way through the process. NIMHE should develop guidance for RDCs and programmes on service user and carer involvement. This should highlight good practice and may be developed as a set of standards by service users and carers. This will give service users and carers a clear idea of what they can expect.
9. NIMHE needs to strengthen its approach in relation to involving diverse groups. It is recommended that NIMHE commissions a review of the literature

in relation to engaging diverse and minority groups as a basis for developing a set of standards and guidance to support the involvement of a diverse range of service users and carers in different aspects of NIMHE's work programme.

10. All programmes and development centres should identify how they are going to broaden the diversity of those involved. This may have implications for the way in which involvement is currently organised and the resources which are currently invested in supporting involvement.
11. NIMHE needs to strengthen the support that is available to service users and carers who become involved. This needs to include a clear process of induction and training as well as ongoing support. Attention needs to be paid to the development needs which arise when there is a change in role, for example moving to being involved at a regional level to being involved at a national level.
12. NIMHE needs to develop an effective communications strategy to support involvement. This needs to be widely accessible to a diverse range of service users and carers.
13. NIMHE should review arrangements with the host organisations to have a standardised approach to ensure that their policies and procedures support the development of service user and carer involvement in NIMHE.
14. NIMHE needs to develop a single payment policy across all the RDCs and programmes. This should be negotiated with the Department of Work and Pensions.
15. NIMHE needs to review the differential payment of staff in service user and carer lead roles across and within RDCs.
16. NIMHE needs to consider how it is going to strengthen the organisational culture to support involvement. Attention should be paid to the development of staff and review of their responsibilities in relation to service user and carer involvement. Each development centre and programme could usefully review where it is currently against the template outlined in section 4.3 as a basis for moving forward.
17. NIMHE needs to develop a way of monitoring the process and outcomes of involvement developed with service users and carers.
18. A clear and costed implementation plan needs to be developed to progress the actions identified. This needs to include the transition from the current arrangements to any new arrangements.
19. NIMHE needs to safeguard the current level of involvement during the establishment of CSIP and work with CSIP to ensure that mental health service user and carer involvement is built into the new organisation and that the proposals outlined in this report are implemented.
20. NIMHE should review the impact of the steps taken as a result of this review in 2 years time.

References

- Aitchison, J. (2001) *Deciding Together – working with people with learning disabilities to plan services and support*. Institute for Applied Health & Social Policy. London.
- Barnes, M. and Wistow, G. (1994) Achieving a strategy for user involvement in community care. *Health and Social Care in the Community* 2 347 – 356.
- Basch, M. (2002) *Customer Culture: How FEDEX and other great companies put the customer first every day*. New Jersey, Financial Times/Prentice Hall.
- Berger, E et al (1996) What's happening with consumer participation? *Australian & New Zealand Journal of Mental Health Nursing* 5 (3) 131 – 135.
- Beresford P. (2002). User Involvement in Research and Evaluation: Liberation or Regulation? *Social Policy and Society* 1:2, 95-105.
- Black, K. and Shillitoe, R. (1997) Developing mental health services sensitive to women's needs. *British Journal of Health Care Management* 3 (1) 27-29.
- Borrill, C., Carletta, J., Carter, A., Dawson, J., Garrod, S., Rees, A., Richards, A. Shapiro, D & West, M. (2001). *The effectiveness of Health Care Teams in the National Health Service*. Aston University.
- Burns, D., Hambleton R., Hogget P (1994). *The Politics of Decentralisation: Revitalising Local Democracy*. Palgrave Macmillan.
- Chamberlain, A. (1993) Working towards user-led services through a mental health forum. *Community Health Action* 8, 6 – 8.
- Carr, S. (2004) Has service user participation made a difference to social care services? *Social Care Institute for Excellence (SCIE) The Policy Press*.
- Carter, T. and Beresford, P. (2000) *Age and Change: models of involvement of older people*. Joseph Rowntree Foundation, York Publishing Services.
- Christianson, P. (2004) *Children's Participation in Ethnographic Research: Issues of Power and Representation*.
- Crawford, M., Rutter, D. and Thelwall, S. (2003) *User involvement in change management: A review of the literature, Report to NHS Service Delivery and Organisational Research Development Programme (NHS SDO)*.
- Danso, C., Greaves, H., Howell, S., Ryan, M., Sinclair, R. and Tunnard, J. (2003) *The involvement of children and young people in promoting change and enhancing the quality of social care*. National Children's Bureau.
- Davis, J. & Edwards, R. (2004) Setting the Agenda: Social Inclusion, Children and Young People *Children & Society* 18 p 97 – 105.
- Dening, T. and Lawton, C. (1998) The role of carers in evaluating mental health services for older people. *International Journal of Geriatric Psychiatry* 13 (12) 863 – 870.
- Department of Health (2001) *The National Service Framework for Older People*. Department of Health, London.

- Donnelly, E. (2003) *A Review of Consultation Initiatives Carried Out with Children and Young People in Liverpool: 1999 – 2002*. Commissioned by the NSPCC and Liverpool Children's Fund. Liverpool City Council.
- Godfrey, M., Callaghan, G., Johnson, L. & Waddington, E. (2003). *Supporting people: a guide to user involvement for organisations providing housing related support services*. Office of the Deputy Prime Minister. London.
- Gregory, M., Newbigging, K., Cole, A. & Pearsall, A. (2003) *Working together – developing and providing services for people with learning disabilities and mental health problems*. Institute for Applied Health & Social Policy. London.
- Hill, M., Davis, J. Prout, A. & Tisdall, K. (2004) Moving the Participation Agenda Forward. *Children & Society* 18, 77 – 96.
- Institute for Applied Health & Social Policy (IAHSP) (2003), *From Communication and Consultation to Partnership and User Control: involving people who use services in planning their own care and strategic service development*. Unpublished working paper.
- Johnson, M. (2002) *Involvement of Black & Minority Ethnic Service Users in Health Research*. Leicester, Mary Seacole Research Centre.
- Joseph Rowntree Foundation (2004). *Older people shaping policy and practice*. York. Joseph Rowntree Foundation.
- King, M. & McKeown, E. (principal authors) (2003) *Mental health and social wellbeing of gay men, lesbians and bisexuals in England and Wales*. MIND London.
- Lewis, J. (1997) Involving users in bringing about change. *Research Policy and Planning*. 15 (2) 16 -19.
- McNeish, D. & Newman, T. (2002) *Involving children and young people in decision making*, McNeish, D., Newman, H., & Roberts, H. (Eds) . What works for children? *Effective Services for Children and Families*. Open University Press. Buckingham.
- Middleton, P., Stanton, P. & Renouf, N. (2004). Consumer consultants in mental health services: addressing the challenges. *Journal of Mental Health*, Vol. 13, 5, 507-518.
- National Schizophrenia Fellowship (1997) *How to involve service users and carers in planning, running and monitoring care services and curriculum development*. Kingston-upon-Thames, National Schizophrenia Fellowship.
- Nuffield Institute, ADSS, Local Government Association, Audit Commission, Better Government for Older People and the Joseph Rowntree Foundation (2004). *Public Services for Tomorrows Older Citizens: Changing Attitudes to Ageing*. Joint statement. www.nuffield.leeds.ac.uk/databases/publications.asp
- Peck, E., Gulliver, P. & Towell, D. (2002). Information, consultation or control: User involvement in mental health services in England at the turn of the century. *Journal of Mental Health* 11, 441-451.
- Poulton, B. (1999) User involvement in identifying health needs and shaping and evaluating services: is it being realised? *Journal of Advanced Nursing* 30 (6) 1289 – 1296.
- Rai-Atkins, A. (2002) *Best Practice in Mental Health: Advocacy for African, Caribbean & South Asian Communities*. Bristol, Policy Press.

- Robson, P., Begum, N. and Lock, M. (2003) Joseph Rowntree Foundation Findings: *Increasing user involvement in voluntary organisations*. York: Joseph Rowntree Foundation.
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wyles, T. (2002). *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDA).
- Royal Liverpool Children's NHS Trust (2004). *Priority Research*.
- Rudat, K. (1994) *Black and Minority Ethnic Groups in England*, London, Health Education Authority.
- Ryan, T. & Bamber, C. (2002) A survey of policy and practice on expenses and other payments to mental health service users and carers participating in service development *Journal of Mental Health* 11 (6) 635 – 644.
- SDC (2001) *Route Map to User and Carer Participation*. Scottish Development Centre for mental health. Edinburgh.
- Seedhouse, D. & Lovett, L. (1992). *Practical Medical Ethics*. Wiley. Chichester.
- Simpson, E., House, A. and Barkham, M. (2002) *A guide to involving users, ex-users and carers in mental health service planning, delivery or research: a health technology approach*. Academic Unit of Psychiatry and Behavioural Sciences University of Leeds.
- Sinclair, R. (2004) Participation in Practice: making it Meaningful, Effective and Sustainable *Children and Society* 18 p 106 – 118.
- Tang, M. & Cunningham, C. (1994) Ways of saying. *Health Services Journal*. 104 (5420) p 28 – 30.
- Thornton, P. (2000) *Older people speaking out: developing opportunities for influence*. Joseph Rowntree Foundation. York Publishing Service.
- Took, M. (1999) Involving service users and carers. *Journal of Psychiatric & Mental Health Nursing* 6 (6) 485 – 487.
- Truman, C. and Raine, P. (2002) Experience and meaning of user involvement: some explorations from a community mental health project. *Health and Social Care in the Community*. 10 (3) 136 – 143.
- Valuing People Support Team and NIMHE (2004). *Green Light: How good are your mental health services for people with learning disabilities?*
- Wallcraft, J. (2003). *The mental health service user movement in England*. SCMH.
- Walls, P & Sashidran, S. (2003) *Real Voices – Survey findings from a series of community consultation events involving black and minority ethnic groups in England*. Department of Health. London.
- Wardale, L. & Troake, S. (2003) *Keeping the Family in Mind*. Branados, Liverpool.
- Wood, J. and Wilson-Barnett (1999) The influence of user involvement on the learning of mental health nursing students. *NT Research* 4 (4) 257 – 270.

Appendix 1 Project Team and Reference Group

Project Team

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Patricia Chambers	Associate, HASCAS
Tina Coldham	Associate, HASCAS
Rob Hughes	Associate, HASCAS
Karen Newbigging	Director of Mental Health, HASCAS
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Additional expertise and comment provided by Peter Ferns and Peter Beresford

Reference Group

Carey Bamber/ Oi Mei Li	Service User & Carer Lead, NIMHE North West
Malcolm Barrett	Service User Lead, South East DC
Peter Beresford	Shaping Our Lives
Laurie Bryant	National Service User Lead: Service Development Team, NIMHE
Barbara Crosland	Service User Lead, NIMHE West Midlands
Colin Gell/Moira Kerr	Service User Leads, NIMHE East Midlands Development Centre
Beverley Gray	Equalities
Simon Heyes / Lucy Pearce	Recovery Lead/Carer Lead, South West Development Centre
Elaine Leeming/Malcolm Rutt	Carer Leads, North East, Yorkshire and Humber Development Centre
Mark Leveson Centre	Service User Lead, London Development for Mental Health
Alastair McIntyre	Programme Lead
Reg McKenna	Experts by Experience
Albert Persaud	Experts by Experience
Sally Prescott	Project Lead and Deputy Director, North East, Yorkshire and Humber Development Centre
Sue Ramprogus	Director of Mental Health
Ed Stanley	Experts by Experience
Mike Took	Experts by Experience
Georgina Wakefield	Carer Lead, NIMHE Eastern
Jan Wallcraft	Experts by Experience

Plus members of the HASCAS project team

Appendix 2 Focus Groups and Meetings Attended

1. Focus Groups

Focus Group	Venue	Target Group
Open event: NIMHE conference	Brighton 22.6.04	Service users and carers attending the NIMHE conference
EbE Eastern	15.7.04	Service users and carers involved in the Eastern region
SE Leadership Course	24.8.04	Service users involved in the South East region
Experts by Experience Focus Group	Birmingham 14.9.04	Members of the Experts by Experience Group
Black and Minority Ethnic Community event	Birmingham 15.9.04	People from black and minority ethnic communities within the West Midlands and nationally
NIMHE Eastern Annual Conference	23.9.04	Service users involved in the Eastern region
Carers Focus Group	London 4.10.04	Carers in London
Children and Young People	Liverpool 7.10.04	Voluntary and statutory sector organisations (nationally) and children and young people in the North West
Older People	Durham 7.10.04	People with expertise of developing involvement for older people, including those with dementia, in the North East

Meetings Attended

Meeting	Date
Service Users in Partnership, WM	8.7.04
Service Users Reference Group, WM	8.7.04
Carers in Partnership, WM	13.7.04
Service User Participation Party London	17.8.04
National EbE group	4.5.04, 8.7.04 12.11.04
LIT NW Carers Group	17.9.04
National Personality Disorder Programme	5.11.04

Additional Papers Received:

East Midlands Service User Consultation Events 10.5.04 and 11.5.04

"What do we need to champion?: NIMHE North and North East Regional Champion Consultation Report by Dr. Rufus May, September 2003.

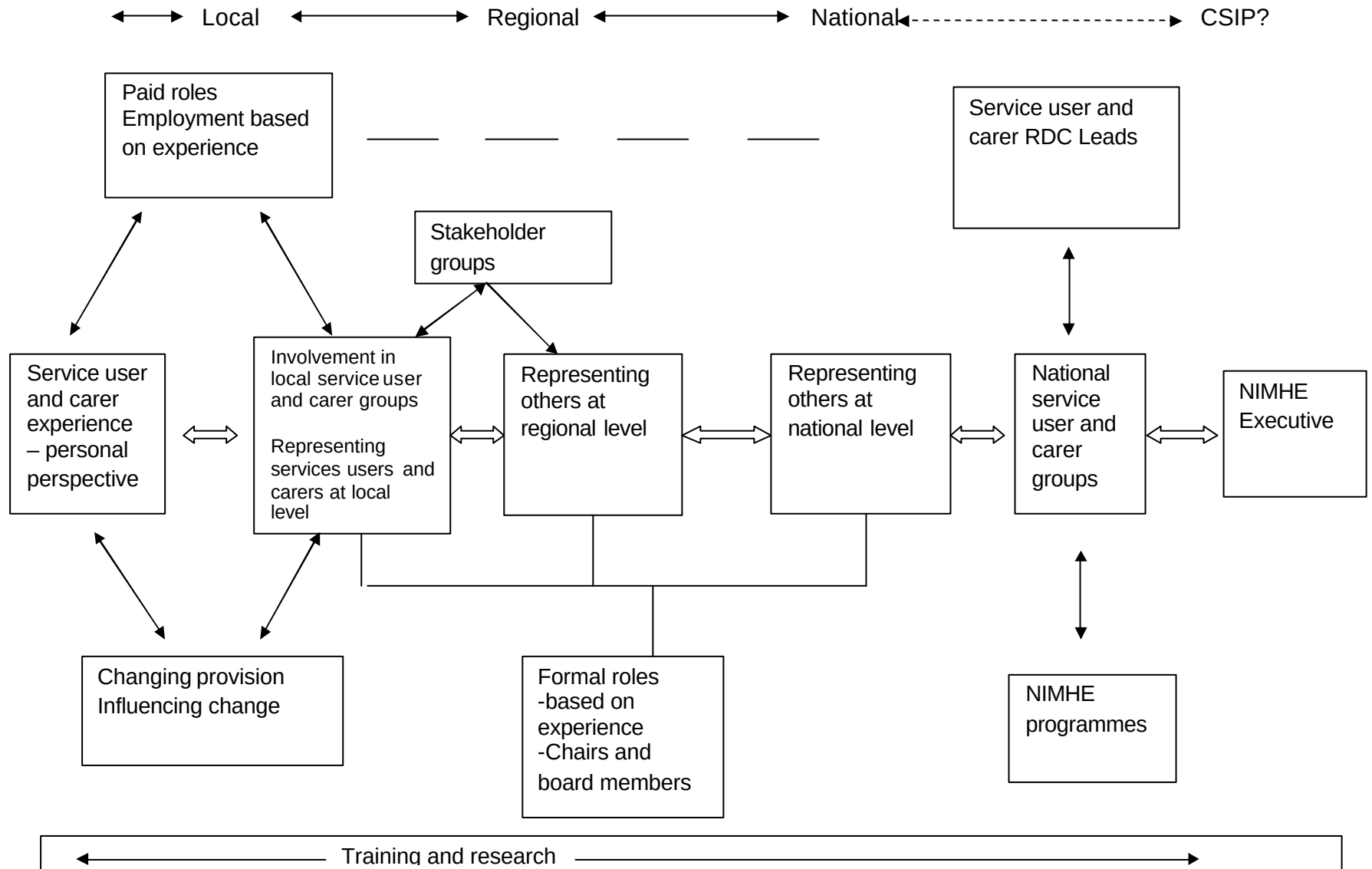
National Strategic Partnership Terms of Reference, May 2003

Experts by Experience constitution (May, 2003) and interim policy on service user and carer family representation

Appendix 3 A route map for involvement in Mental Health

Identifying what you want to get involved in	Which organisation could you get involved in?
Influencing your personal care and support	Your Care coordinator about , or the person you care for, care plan Local service user and carer forums Getting extra support through advocacy services or Patient Advice and Liaison Services
Influencing organisations providing support	Local service user and/or carer groups often organised by organisations such as Mind, MACA and Rethink Patient and Public Forums for the Mental Health Trust
Influencing the planning of mental health services	Local Implementation Team or local strategy group Patient and Public Forum for your Primary Care Trust
Influencing how change happens in mental health services and in policy	NIMHE through your local Regional Development Centre Organisations that have a campaign function, such as Mind, and specific service user or carer lobbying groups
Influencing services to change through reviewing mental health services against standards	Healthcare Commission

Appendix 4: Proposed Representative Structure



Glossary

Carer	Anyone who has a significant caring role for someone who experiences mental distress
Care Services Improvement Partnership (CSIP)	A new organisation being 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 is 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