

# **Service User and Carer Involvement in The National Mental Health Development Unit**

## **Scoping Report November 2009**

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## **A Glossary of Acronyms**

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|--------|---|
| CSIP   | Care Service Improvement Partnership – CSIP was set up in 2005 with a budget of £39m to support the delivery of DH social care and health policy. It comprised seven programmes including the National Institute for Mental Health in England (NIMHE).  |
| HASCAS | The Health and Social Care Advisory Service. An evidenced based service development organisation working in all aspects of mental health and older people’s services across the health and social care continuum.   |
| IAPT   | Increasing Access to Psychological Therapies – one of the NMHDU programmes  |
| IMHA   | Implementation of the Mental Health Act – one of the workstreams under the Care Pathways programme  |
| IoP    | Institute of Psychiatry, King’s College London  |
| MARD   | Making a Real Difference – the programme established under NIMHE to support user and carer involvement  |
| MHF    | Mental Health Foundation – national mental health charity<br><a href="http://www.mhf.org.uk">www.mhf.org.uk</a>   |
| NIMHE  | National Institute for Mental Health, England   |
| NMHDU  | National Mental Health Development Unit: launched in April 2009, it consists of a small central team and a range of programmes funded by both the Department of Health and the NHS to provide national support for implementing mental health policy by advising on national and international best practice to improve mental health and mental health services. |
| NSUN   | National Survivor User Network – a network set up to engage and support the wide diversity of mental health service users and survivors across England in order to strengthen the user voice.   |
| PSA    | Public Service Agreement <i>PSAs are a clear commitment to the public on what they can expect for their money and each agreement sets out explicitly which minister is accountable for delivery of targets underpinning that commitment.</i>  |
| SPN    | Social Perspectives Network – The Social Perspectives Network is a coalition of service users / survivors, carers, policy makers, academics, students, and practitioners interested in how social factors both  |

contribute to people becoming distressed, and play a crucial part in promoting people's recovery.

## **I Introduction**

This report outlines the status of user and carer involvement in the National Mental Health Development Unit (NMHDU), proposes baseline standards for good practice and recommends next steps for the future of involvement in NMHDU. The work was undertaken by a consultant (AF) working for the partnership of organisations who won the tender to support user and carer involvement in NMHDU.

### **Background**

The National Mental Health Development Unit (NMHDU) supports the implementation and delivery of national mental health policy. The key functions of the NMHDU are to provide high level support to the Department of Health, the NHS and social care partners in developing and implementing mental health policy, by commissioning or providing:

- specialist expertise in agreed priority areas of policy and delivery
- effective knowledge transfer in relation to research, evidence and good practice
- translation of national policies into practical deliverables to achieve desired outcomes
- coordination of national activity to support regional and local delivery.

In April 2009 NMHDU invited applications for the ***“Delivery of Service User and Carer Involvement in the work of NMHDU to assure and improve programme outcomes and to increase active participation in all aspects of our work”***. The tender was won by a partnership bid. The National Survivor User Network (NSUN) – hosted by Together – is the lead organisation, partnered by Afiya Trust, Attend, Equalities, the Mental Health Foundation and the Social Perspectives Network (SPN). The proposal draws on the expertise of each organisation and their respective networks.

The predecessors of NMHDU – NIMHE – have left a legacy to this piece of work in the form of many individuals and pieces of work demonstrating user and carer activity within individual programmes. Some of these appear in this report. Furthermore, two previous reports explored routes to strengthening user and carer involvement through the ‘Making a Real Difference’ projects (HASCAS, 2005; HASCAS, MHF and Together, 2007). This report builds on the recommendations of each of these two reports. The recommendations from the first of these (HASCAS, 2005) are given in Appendix A; the recommendations from the second are given below.

It is important to note that the Making a Real Difference products were largely formulated upon the recommendations from the HASCAS (2005) report entitled ‘Making a Real Difference: Strengthening User and Carer Involvement in NIMHE’.

**Recommendations of scoping review report undertaken by HASCAS, MHF and Together (2007) – strengthening user and carer involvement in NIMHE**

- Service users and carers should have independent but connected national networks
- The model adopted should build on existing groups and individuals so that they can work together more effectively
- Sustainable networks need independent funding from a range of diverse sources
- Funding needs to be long term - five years rather than one or three
- Both national networks should be independent of, but supported by NIMHE/CSIP
- Leadership within NIMHE/CSIP should be at the highest possible level
- NIMHE/CSIP and other large organisations (voluntary organisations for example) should offer a range of resources to support national networks for service users and carers

Since the above report was published, a number of developments have taken place, the main one of which being the establishment of NSUN (the National Survivor User Network). There is no equivalent carer network at present, but the partnership carrying out this work includes the organisation Attend, which hosts the **Supporting Carers Better Network**, which is for all people supporting carers in mental health in England. It aims to identify and share good practice, and connect people.

### **Aims**

The aim of this piece of work was to scope current user and carer involvement in NMH DU programmes and to produce a baseline report on the user and carer involvement issues and good practice reported by NMH DU programmes. As part of this scoping exercise, it was also intended to review the MARD products with a view to their future use within NMH DU.

## **II Methods**

The consultant (AF) with an assistant (VF) met and/or spoke to as many of the programme and workstream leads in the NMH DU as was feasible within the time period:

- Improving Access to Psychological Therapies
- Improving Mental Health Care Pathways

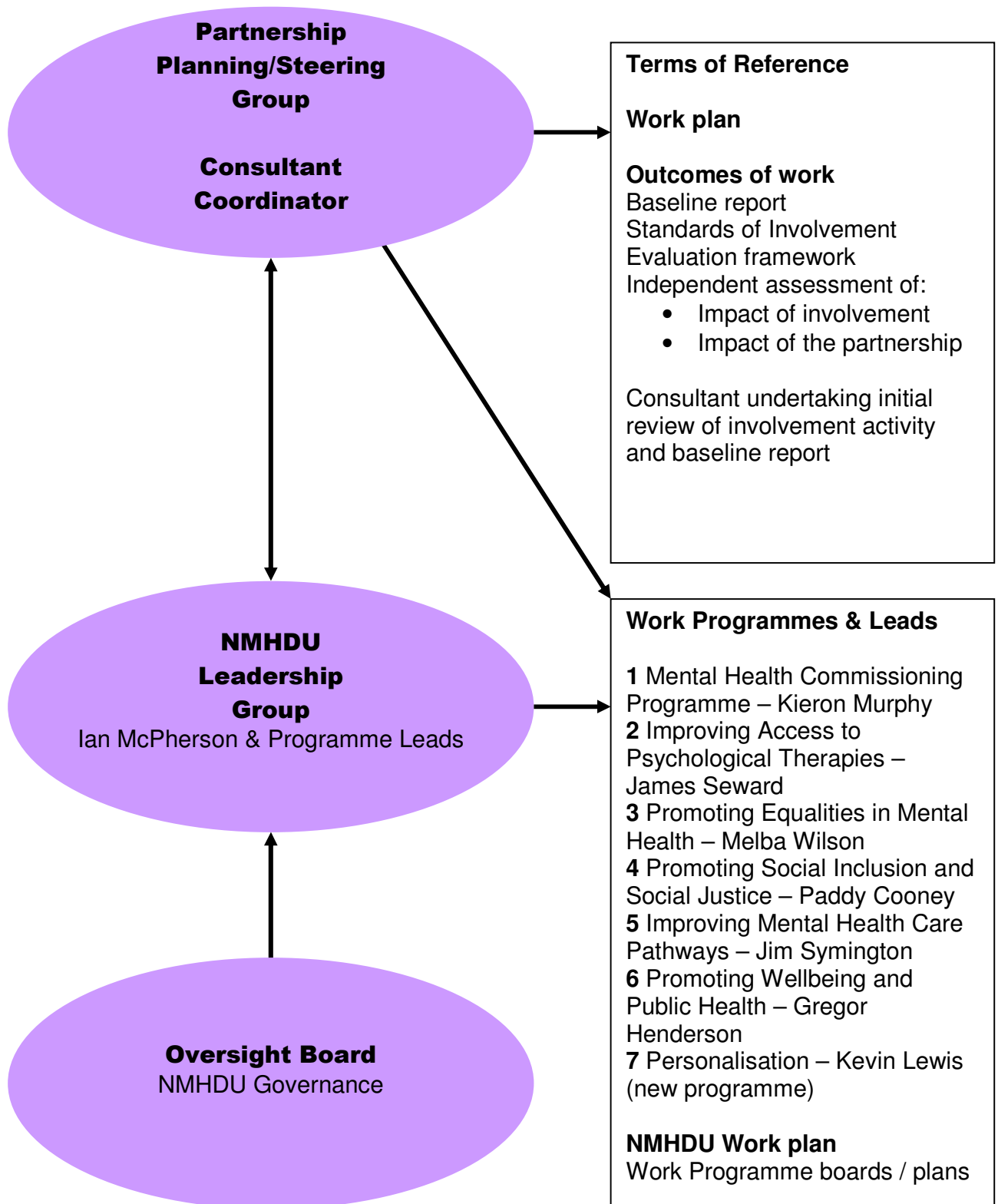
- Promoting Equalities in Mental Health
- Social Inclusion & Social Justice in Mental Health
- Wellbeing & Public Mental Health
- World Class Mental Health Commissioning

Appendix B details those people who were contacted for information during the course of this work. A total of 14 face-to-face meetings, five telephone interviews and three questionnaires were completed. The key themes explored with individuals were as follows:

- Basic information about the programme/workstream
- User and carer involvement – past and present, including BME involvement
- Contact details for the above
- Awareness of and use of MARD products
- Good practice examples of user and carer involvement

In addition, the consultant reviewed the MARD products with the help of 'expert witnesses' both within and beyond the NMH DU: for example, authors of the previous reports on MARD, people involved in developing the products and anyone interviewed during the course of this work who had used them. The steering group were also invited to give their views.

**NMHDU relationships chart**



Relationships between individual organisations and groups and NMHDU work programmes to be explored.

### **III Service User and Carer Involvement in NMH DU: an outline**

In this section, each programme is taken in turn and the user and carer involvement features and issues are described. It is important to note that the information contained here is not necessarily comprehensive, as it was not possible to speak to everyone within the given time period. Apologies are given for any inaccuracies.

One of the determining factors for the level of involvement is the age and stage of the programme. Most of the programmes that precede NMH DU have some history of user and carer involvement from NIMHE.

#### **1. Improving Access to Psychological Therapies (IAPT)**

*Lead: James Seward*

This programme is relatively new, but precedes the establishment of NMH DU. At the governance level, there is formal user and carer involvement in the persons of Laurie Bryant and Lu Duhig. Each is employed for 0.5 days per week as National Advisors for IAPT (there are 7 or 8 in total). IAPT originally had a couple of pilot sites, these have now expanded to around 130 sites, as a result of which involvement is difficult to organise. LB and LD are currently aiming to work with the Regional leads to capture good practice locally for a website of ideas and suggestions. The challenge for the IAPT programme (confirmed in interview with Liam Gilfellon, NE lead for IAPT) is to achieve local user and carer involvement. As it is a primary care based programme, it is harder to engage people as they do not tend to identify or organise themselves as service users at this level; LG suggested that, in effect, carers may be their service users.

LB and LD sit on all the boards, so the programme definitely demonstrates its commitment to involving people. There is however a limit to what they can do in 0.5 days per week. They would like to negotiate their role; they would like it to be more of an ambassadorial role, with their work going out into the regions. There is some frustration that they cannot move more quickly or do more to extend and support involvement in the regions. There are other service users and carers involved from previous NIMHE work in the regions – e.g. Paul Johnson in the North East and Fenella Lemonsky in London, who has been working on the CSIP ‘New Ways of Working’ for psychological therapists.

#### **2. Improving Mental Health Care Pathways**

*Lead: Jim Symington*

Most of the workstreams that fall within this programme have a substantial history, and one or two are coming to an end. Hence, some of the involvement discussed here is either ended or within sight of ending. There is no evidence of user or carer involvement at the board/governance level of the programme as a whole.

## 2.1 Implementation of the Mental Health Act

*Lead: Malcolm King*

Service user and carer involvement within this workstream appears to have been good. Sarah Dewey (service user) was employed as a member of the team for nearly two years. She does not regard this as 'involvement' as such, but it does represent a way of ensuring that a service user (or carer) perspective is introduced into the delivery of a workstream or programme. In this case, the main task was training people in the implementation of the mental health act. The experience was positive; Sarah was regarded as a full member of the team, felt well supported and gained in confidence as a result of the position. There was also a Service User & Carer group (SUCs) for which we have the contact details. There is some suggestion that there were difficulties with this group, but also that it worked quite well (see evaluation report by MHF); at the time of writing, contact had not been made with members of this group.

## 2.2 Personality Disorder

*Lead: Nick Benefield*

The information on this workstream is based on a questionnaire; no interviews took place with the programme leads. However, one service user lead at a regional level was spoken to. Service user and carer involvement in this workstream appears to have been quite comprehensive, with involvement noted in training and research. With the demise of NIMHE and CSIP, the local service user and carer leads have been (or are being) disbanded. The clinical advisor (RH) suggests that the programme has demonstrated good practice through its close working relationships, citing the KUF (Knowledge and Understanding Framework) development and implementation as a particular example of this.

## 2.3 Acute Care

*Lead: Yvonne Stoddart*

This programme is likely to continue. They are currently working towards an 'Acute Care Declaration' which will entail voluntary sign-up from Trusts etc. There is a service user and a carer on the Board. BME links have been loose – through the Equalities programme. The programme sponsored the Star Wards initiative, set up by a service user, Marion Janner. They regard this as good practice and as user-led. Another initiative they funded is the Triangle of Care – initiated by a carer – which is also regarded as good practice.

With the re-formation of the programme around the Acute Care Declaration, there will be the need to re-visit the governance structure to reflect the new task groups. Service user and carer involvement will change – YS hopes there will be more involvement in the future structure.

## 2.4 Early Intervention

*Leads: David Shiers and Jo Smith*

This programme was part set up by a carer, David Shiers. From the start, the programme has been influenced by service users and carers in some way; e.g. when they first got a group of people together to establish their 'Early Psychosis Declaration', this group included Ron Coleman and Sheena – a carer. They influenced the choice of outcomes to be measured as part of the declaration.. 'nice idea, shame about the outcomes'.. on the basis that the original ones were too clinical. The programme also linked closely with Rethink for a while, which gave potential access to users and carers. DS says the programme involves users and carers in all their work – often as case examples and narratives for training, podcasts, etc.

## 2.5 Dual Diagnosis

*Leads: Ann Gorry / Tom Dodd*

Information on this workstream has been gained from questionnaire only. The programme encourages service user and carer involvement at a local level. They have involved people in their conferences and events, and have produced a product with carers: 'making a difference – a carers dual diagnosis resource'. They say that they are in the process of developing a service user focussed outcome framework, and have commissioned a consultant in partnership with service users to produce this product.

# **3. Equalities**

*Lead: Melba Wilson*

## 3.1 Delivering Race Equality

This innovative programme is a five year plan established to improve access, outcomes and experiences for people with mental health needs. It is designed to tackle mental health inequalities for all people of Black and Minority Ethnic origin, including people of Irish or Mediterranean origin and East European migrants. The programme set up the DRE Ambassadors programme, which is thought to be a good model for involvement. They had a regional process for identifying representatives and a national structure to support that, with the support and leadership of Julie Charles, an external consultant.

They recruited people through the regional RE leads: aiming for 2-3 people per SHA region. Now have a total of around 32 service users and carers, with 2-3 in every region. The proportion is probably around 80/20 service users/carers. There are some very good people, and they have varying skills and capacity for the work. The role is to link up regional leads, local services and use the Equality Impact Assessment, work as a 'critical friend' on what is and is not working well in each region. It is based on ENC's ICAN model. Julie said that advocacy and mentoring are at the basis of all that they do.

They are now concerned with skilling the newer people up in the transition from DRE to become equality ambassadors. MW said that there is a need for structure and

processes and that they are getting there, but need help to signpost how to make the transition to the wider equalities framework. In conclusion, she is optimistic and hopeful that NSUN partnership will help to take things forward, to follow through where NIMHE left off.

### 3.2 Gender and women's mental health

*Sue Waterhouse*

This programme works to address the acknowledged deficits in mental health service delivery in meeting the needs of women. Programme priorities include: ensuring an integrated approach to equalities, implementing Public Sector Gender Duty in mental health provision, workforce development to build in an awareness of gender equality to support the provision of gender sensitive services.

*No information obtained on user and carer involvement*

### 3.3 Later life

*Nadine Schofield*

This programme provides support to local economies seeking to improve services that pay special attention to mental health and wellbeing of people in later life. It promotes an appropriate interpretation of age-equality in mental health services by scoping the nature and extent of age-based discriminatory practice.

*No information obtained on user and carer involvement.*

## **4. Social Inclusion and Social Justice (PSA 16<sup>1</sup>)**

*4 interviews – 2 on Shift, 2 on PSA 16*

### 4.1 PSA 16

This programme follows through some of the work of the National Social Inclusion Programme (NSIP), taking the themes of employment and housing only. The programme is commissioned by the Department of Health under the Health Inequalities programme; hence the NMH DU is not the commissioner. The work is to be done by March 2011. The ambition of PSA 16 is to embed housing and employment outcomes within other programmes.

With regard to involvement issues, its predecessor (NSIP) had achieved some good practice and this has not yet been carried through into the new programme. Towards the end of NSIP they had a total of four expert advisors, who had been recruited from Shift, and a reference group of 15. The reference group was recruited with role descriptions following a reorganisation of involvement in NSIP.

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<sup>1</sup> PSA 16 is concerned with ensuring that the most socially excluded adults are offered the chance to get back on a path to a more successful life, by increasing the proportion of at-risk individuals in: settled accommodation; and employment, education or training.

Now, Zoe Robinson, who leads on PSA 16 (under Paddy Cooney) feels that involvement is a serious gap in the new programme. She is used to working 'co-productively' and would like to re-engage with the previous reference group if possible. Alternatively, she talked of possibly working with the NSUN partnership. She said that she would appreciate advice on how to work co-productively with people on this; she probably has about £15k in the budget. She is concerned that people may not be as interested in engaging with a programme focussed solely on employment and housing (as against the former broader social inclusion programme).

#### 4.2 Shift

The Shift project is widely regarded as demonstrating good practice with regard to the involvement of service users and carers. The programme itself is concerned with shifting stigma through working with audiences to raise awareness and combat discrimination, helping people by providing the tools to get started, but then leaving the responsibility with the organisation to challenge discrimination. The programme has five work areas: research (it carries out three regular surveys of stigma), employment, media, sport, and BME communities. Shift has strong links with Equalities programme through Melba Wilson.

Shift has a group of 14 Expert Advisors (service users and carers) who are involved in all of these things to a greater or lesser extent. They have been involved in all aspects of the work, and have formed part of the team delivering the work. They are very involved in the employment and the BME work, less so in media and sport. Shift also has the Speaker's Bureau – there are about 60 people registered on that.

At present, the Expert Advisors are working on bringing together their experiences of what constitutes meaningful involvement, writing something for the web as a legacy of their work, which will be very useful for NSUN and for the other programmes to learn from.

## **5. Promoting Wellbeing and Public Mental Health**

*/ interview*

The aim of this programme is to improve population mental health and well-being; also, it will be working to encourage the DH to value prevention and promotion as highly as treatment. It is entirely new and based on the New Horizons programme. At present, its future is unclear. There is no (obvious) user and carer involvement in the programme as yet; although some engagement with service users and carers has taken place in consulting about New Horizons. Much of the focus is on commissioning for wellbeing (obvious direct link to Commissioning programme), which is being led by Karen Newbigging; she may be involving service users and carers.

The challenge for the future of involvement in this programme is to engage members of the wider population to input regarding what they would like to support wellbeing. Secondly, the programme will also wish to engage with more vulnerable groups,

including those living with mental illness, to find out what they want to support their mental health and wellbeing. This programme has implications for all Government departments but primarily for local government.

## **6. Commissioning**

*1 interview*

This programme is small compared to many of the others, and – like some – its future is unclear at this time. Its work is divided into three: policy, commissioning (practical products and services) and workforce skills. Until recently, the programme had Laurie Bryant and Lu Duhig sitting on the Board, but with the restructure into NMH DU this became no longer possible. They are keen to have someone, perhaps from NSUN, to take their place. In addition, they are commissioning a piece of work in the NW to look at how to support service users to be involved in commissioning. Kieron Murphy had not come across the MARD guidelines on involvement in commissioning.

### **Summary of Involvement**

Clearly, the programmes are at different stages of development with regard to their own work and hence to the involvement of service users and carers. There is a wealth of experience and good practice to build upon from the legacy of NIMHE, but there is also a risk of losing some of this as another transition in the form of NMH DU takes place.

Some of that history is held by individuals; for example, Laurie Bryant and Lu Duhig, who once held more significant roles within the Service Improvement Programme and Making a Real Difference, and were members of the Experts by Experience group. Other history is held within different work programmes which have in some cases come to an end but which during their lifetimes demonstrated significant good practice; e.g. NSIP.

Where a role has not worked well, it is often because the role was unclear in the first place. Perhaps the least successful has been that of individuals sitting on advisory groups or reference groups. Criticisms have centred on the issue of whether or not the people sitting on a group are ‘representative’ of others, or of any specified group or constituency. This is often an uncomfortable role to occupy if its purpose is unclear. It is also a role that can invite criticism from outside.

A related issue identified during consultations was that on occasions, the identity of ‘user’ and ‘carer’ is blurred or unclear, and that representatives of voluntary organisations are confused as being representatives of service users or carers. For the record, this is not the case unless the voluntary organisation is user- or carer-controlled.

A significant issue is the finding that there appeared to be few black and minority ethnic service users or carers involved in NMHDU, outside of the Equalities programme. Some workstreams had made some headway through linking with the DRE programme in some way, but sometimes this was to engage a number of people to attend an event, rather than in an ongoing thread of involvement. Shift is an exception to this.

## **Information Gaps**

Gaps in the information gathered include:

- Gender/women's mental health and mental health of later life (Equalities programme)
- Violence and abuse (Pathways to Care)
- Dual diagnosis (Pathways to Care)– only questionnaire info
- IAPT – Programme Lead and other regional leads could offer further information
- Service users and carers involved in the Service User and Carer group (IMHA Pathways to Care)
- Service users and carers involved in Personality Disorder (Pathways to Care)
- Service users and carers involved in Acute Care (Pathways to Care)
- Personalisation – new programme

## **Involvement Gaps**

1. Across most programmes, there is a need for the involvement of more BME service users and carers. This may be addressed in a number of ways, e.g.
  - a. Ensuring that there is a range of different methods for becoming involved;
  - b. Engaging with networks such as the DRE/Equalities Ambassadors, the Afiya Trust and the Catchafiya network.
  - c. Learning from other programmes – e.g. DRE Ambassadors programme, Shift,
2. The newer programmes have a relatively blank slate (e.g. Wellbeing) and have the advantage of being able to learn from the experiences of other programmes.
3. Gaps at the Board /governance levels in some programmes may be partly due to waiting for the NSUN partnership to act. In some cases, there may have been a lack of role clarity for people sitting on committees and boards.
4. Gaps at the local or grassroots level where a programme does not have a history of involvement, e.g. IAPT (primary care), Wellbeing (public health/general public);
5. PSA 16 has yet to establish its involvement strategy, but is able to build on the experiences of NSIP.
6. There may be other gaps – e.g. Acute Care programme as it re-forms around the Acute Care Declaration;

| Programme               | Workstream   | Involvement - summary   | Good practice examples   |
|-------------------------|--|---|--|
| <b>IAPT</b>             | (Regional delivery sites)<br>3 interviews                        | National advisors (1 carer and 1 service user); some regions also have continued involvement in the form of LINKs <sup>2</sup> : some ex-regional user/carer leads have become LINKs leads. Involvement is a challenge for IAPT because of its primary care focus.  | 2 of the National Advisors to IAPT are: a service user and a carer   |
| <b>Pathways to Care</b> | Implementation of MH Act<br>2 interviews                         | Employed service user (and carer?) as part of the training delivery team; also SUC group – full info not gained on this   | Employment of a service user as a full member of the team was seen and experienced as good practice.   |
|                         | Personality Disorder questionnaire                               | Extensive involvement at national and regional levels; in training; research; policy and planning; local user/carer leads   | Good working relationships – esp. note development of the KUF training and delivery of same.   |
|                         | Acute care<br>Tel. interview                                     | Some involvement historically; more needed in the future with the changes taking place to the programme.<br>BME links loose – need for more.<br>One user led and one carer led initiative sponsored by the programme (Star Wards and Triangle of Care)  | Star Wards – user-led<br>Triangle of Care – carer-led  |
|                         | Early Intervention (finishes Dec 2009)<br>1 interview, and qu're | Involve users and carers in presentations, podcast materials, hothouse events with professionals and use user and carer narratives in their work. Just completed an EI Practice manual about to be published by Blackwell where several chapters have been co-authored with users and carers.<br>National EI Lead role: DS is a carer of a daughter with psychosis and learning disability. | <i>'In this concluding phase of the programme DS has been invited to work with WHO Europe &amp; European Commission to establish user and carer empowerment as per Helsinki declaration. This reflects how the National EI programme has been seen as an example of good practice for user &amp; carer empowerment.'</i> |
|                         | Dual Diagnosis Questionnaire                                     | 1. We have engaged with a number of carers to produce a product for the programme (making a difference – a carers dual diagnosis resource)<br>2. Regionally/locally we encourage and promote service user involvement with any dual diagnosis service   | Not known  |

<sup>2</sup> LINKs are Local Involvement Networks: they replaced patient and public involvement forums from 1 April 2008. LINKs aim to give people a stronger voice in how their health and social care services are planned and delivered. Run by local individuals and groups and independently supported - the role of LINKs is to find out what people want, monitor local services and use their powers to hold health and social care providers to account.

|  |                               |  |   |
|--|-------------------------------|--|---|
|  |                               | developments and encourage this at all levels i.e. commissioning, service providers etc<br>3. We have involved service users and carers at national and regional conferences and events.   |   |
|  | Violence and Abuse            | <i>No information</i>  |   |
| <b>Equalities</b>                                  | DRE                           | Ambassadors programme: 17 ambassadors recruited, at least one in each region. They are now concentrating on skilling these people up and looking for them to make the transition from DRE to equalities ambassadors.   | Ambassadors programme is thought to be good practice. The equality impact assessment they use is also said to be a good practice too.                         |
|  | Gender                        | <i>No information</i>  |   |
|  | Later Life                    | <i>No information</i>  |   |
| <b>Social inclusion and Social Justice (PSA16)</b> | PSA 16<br><i>2 interviews</i> | The team are keen to involve people and to work co-productively; they may re-engage the reference group from NSIP, or aim to work with the NSUN partnership. It is a gap at present.   | NSIP (the programme's predecessor) was regarded as good practice in involvement.  |
|  | Shift<br><i>2 interviews</i>  | Team of 14 Expert Advisors work closely with project staff, some are equal members of the team, deliver the work as much as advise on it.<br>BME : 2 expert advisors lead on this, one an Asian man, they also have close links with Equalities and do some of their work through CDWs – producing a series of DVDs as a resource. | Shift itself is cited as good practice by several interviewees. Expert advisors are capturing their experiences of meaningful involvement for a web resource. |
| <b>Wellbeing</b>                                   | <i>1 interview</i>            | New programme, based in New Horizons plan. No obvious user & carer involvement at the time of interview.   |   |
| <b>Commissioning</b>                               | <i>1 interview</i>            | Commissioning a piece of work in NW on how to support service users to be involved in commissioning.<br>Would like someone to sit on the Programme Board.  | Hope to collect examples of good practice to share via web. [AF – own example in West Sussex PCT]   |

## **IV Good Practice**

Several of the programmes cited examples of good practice in relation to involvement, but only a few examples were also cited by others as demonstrating good practice. Listed here are those examples cited by more than one source as being good practice. Again, this information is based on the interviews undertaken within this particular period of time (mainly October 2009) and so should not be regarded as an exhaustive list.

**1 The Shift programme** and the way in which it has involved service users and carers was identified as good practice by a number of people spoken to during the course of this consultation. The reasons given for this include the following:

- A clear example of people working together successfully to deliver the work; service users and carers regarded as team members;
- Offering a range of different ways of being involved;
- Flexibility – allowing people to choose what they wished to be involved in and how much they wanted to be involved;
- Open and inclusive communications
- Leadership and attitudes (open-minded, creative, inclusive)
- Opportunity to develop/learn skills
- The origins of the project: the expert advisors were recruited first and before the project manager – this meant that Gary came into the post to work with them and hence did not ‘involve’ them; this process was largely accidental, but in retrospect they feel it made for more equal working relationships.
- Expert advisors are capturing their experiences of meaningful involvement for a web resource.

**2 Implementation of the Mental Health Act** employment of a service user as team member. Both the Programme Lead and the service user said that they had gained from the experience, and pointed to this as good practice. Their reasons included:

- Having a clear purpose and role for the service user
- Working alongside, as a member of the team
- Being supported and given due consideration when unwell
- Gaining in skills and confidence; learning from each other

**3 National Social Inclusion Programme** engaged four expert advisors (from Shift) and a reference group of 15 members. The following excerpt is taken from the NSIP 2009 report ‘Vision and Progress’:

“We operate in a co-productive way, ensuring that our work is informed by people who use services themselves, and carers. The Expert Advisors are a small group who work with NSIP to ensure the involvement of people with mental

health problems is maximised across the programme. They also advise on the direction of certain initiatives and provide specific expertise on a range of inclusion areas, including day services, arts, education and employment.

*“I find that much of the knowledge, skills and perspective I have acquired at the national programme around policy, strategy, new ways of thinking and good practice have motivated and inspired me to constantly look for opportunities to implement and develop the values and principles of NSIP.” [NSIP expert advisor]*

The report gives further details of the ways in which both the expert advisors and the reference group worked with the NSIP programme to further its aims. They report that the expert advisors were involved in participating on recruitment panels and in the active measurement of good practice in a range of service settings, contributing to the development of key resources such as the website, evaluation tenders and publications, planning events. The Reference Group, with its 15 formally appointed members, started life in 2005, initially to work specifically on the employment and benefits issues within the programme. However, the collective contribution of the group was such that its perspective broadened to cover the entirety of the work, offering NSIP a practical means of integrating its strategic work with individual experience.

*“Being at the cutting edge of a new form of user involvement, where involvement is no longer the appropriate word, because that puts the onus on the professionals. Cooperation in its literal sense of working together.” [NSIP expert advisor]*

**4 The following programmes** (or elements of them) were cited as good practice by their Programme Lead and/or by another member of the programme itself:

- Early Intervention in Psychosis programme: invited to sit on a WHO Europe advisory board in relation to user empowerment
- Personality Disorder programme: extensive involvement of service users and carers at national and regional levels; in training; research; policy and planning; local user/carer leads; good working relationships based on trust.
- Delivering Race Equalities: ambassadors programme (more information needed)
- Acute care: Star Wards and Triangle of Care
- IAPT: two national advisors are a service user and a carer, with a remit to encourage and support local involvement.

### **Good practice: an overview**

From this overview we might conclude that:

- Some form of recruitment involving the purpose of involvement and role descriptions is advisable;
- Leadership is important: an open and inclusive attitude can create an environment in which involvement can flourish;

- Support is essential, in the form of:
  - Practical/administrative (travel and other arrangements & payments)
  - Project related (what is expected, information, supervision)
  - Emotional (issues arising from involvement, stress)
- Payment needs to be clear and practical
  - And, ideally, prompt
  - Expenses need to be paid on the day
  - Not to be done in a secretive way that implies it is shameful
  - Many people used the MARD guidelines, and were grateful for them
- Communications need to be open and inclusive at all times
  - Being honest and open with people engages their trust
  - Clear and accessible information can be empowering and enables better participation to take place

Some of the issues or themes that arise as good practice are clearly identifiable as good ways of doing things; others, however, are less tangible and have more to do with attitudes and interpersonal relations. In addition, some may occur almost accidentally, in an unplanned way, but appear to have worked well in retrospect. Thus, setting a blueprint for good practice is not always possible or desirable. However, it is possible to give guidance on getting the basics right: issues such as providing clear information, support, training and payment can be both identified and achieved.

**Figure 1: The MARD Good Practice Guidance addresses the following themes:**

- **Be clear**
- **Be inclusive**
- **Treat people equally**
- **Have a positive attitude**
- **Ensure good communication and information**
- **Have good physical accessibility**
- **Adopt a good procedure**
- **Ensure support is available**
- **Have resources available**
- **Create meaningful involvement**
- **Consider all practical issues – before, during and after**

Earlier in the year, the author (AF) undertook a brief literature review of user involvement as part of a piece of consultancy work for a national mental health charity. The results of this are as follows. The review looked at nine documents in detail (listed

in figure 2), with reference to a longer list of mostly older publications and guidelines on the subject (given in Appendix D). The different documents take slightly different approaches or bring different perspectives to the issue of involvement, but there are some significant common themes. These include:

- The importance of **clarity and transparency** in communications with people – about the nature of involvement, the potential for influence in a project, and so on.
- An openness to **change** is vital if involvement is to be meaningful.
- The importance of having a **clear purpose** for involvement.
- The importance of involving people at the **earliest possible opportunity**; this can avoid misunderstandings and maximise the benefits of involvement.
- The importance of providing **adequate support** and **appropriate training**. (Support is in some documents – notably those on research – clearly separated into administrative, supervisory and emotional.)
- The importance of allowing **sufficient time and resources**.
- The importance of ensuring **accessibility**, both physical and language-related.
- The value of allowing **flexibility** to enable a range of people to participate and to overcome or work through periods of distress.
- An acknowledgement of the need for **diversity** is vital; human beings are highly diverse, have a wide range of different experiences and come from different communities. Particular consideration needs to be given to involving people from black and minority ethnic communities, and people in forensic services, for whom involvement is less easily accessible.
- This means adopting a **range of different approaches** to user involvement – not a ‘one size fits all’ approach.
- Most refer to a need for clarity, flexibility and consistency around **payment**; although in some cases (e.g. governance of registered charities, individual choice) payment of fees may not be feasible or desirable.

**Figure 2: The nine documents reviewed**

1. 'How managers can help users to bring about change in the NHS' SDO Briefing Paper 2004: reviews two literature reviews
2. Good practice guides on user and carer involvement written by TwoCan Associates with LMCA
3. 'Hear by Right' National Youth Agency resources for involving children and young people (includes self-assessment tool)
4. 2007 literature review on 'empowerment, employability and service user involvement' Scottish Poverty Information Unit Service User Involvement Project.
5. SURGE 2005 Guidance for Service User Involvement in the Mental Health Research Network.
6. Welsh Assembly Government: Stronger in Partnership 2 – Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales, October 2008
7. Kalathil, J. (2008) *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. National Service User Network in collaboration with Catch-a-Fiya
8. Robson P, Begum N and Locke M. (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*. York: The Policy Press in association with the Joseph Rowntree Foundation
9. Wallcraft, J., Read, J. & Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*. London: The Sainsbury Centre for Mental Health.

## **V Making a Real Difference: the MARD products**

There was considerable consensus regarding the use, non-use, role and value of the MARD products. See Appendix B for a full list of the MARD products.

- A great deal of work went into the development of the MARD products, including the direct work of service users and carers as well as extensive consultation, resulting in the creation of some valuable resources;
- They were – and are now – difficult to locate and have therefore remained unused to a large extent. They seemed to disappear from the website with the demise of NIMHE, or became difficult to find in the KC (Knowledge Community) site;
- Some frustration exists amongst those people involved in their development as a result of this. It is as if they became inaccessible just as they were completed;
- The most used of the products has undoubtedly been the payments policy. Many people had only used this one. This will require updating in line with current benefits or other policy changes;
  - However, the Shift programme chose to pay everyone the same rate regardless of the nature of the work, in order to remove the implicit hierarchy in the different activities
- Some people found the products to be too large and unwieldy and hence not easy to access the information required;
- Comment was made about the evaluation product only reflecting one side of the picture (and not evaluating the service user/carer input to a project or programme);

### **Recommendations for the MARD products are as follows:**

1. Design a means of navigating through the products (perhaps based on a FAQs approach); and/or
2. Design an easily accessible summary based on the summaries of each product – linked to the full documents for those who wish to read them or who need to access the full information;
3. Re-brand the products for NMH DU and re-launch them with access via the NSUN website as well as NMH DU website.

## **VI Baseline standards**

In setting baseline standards for involvement, consideration needs to be given both to issues of good practice and to the potential for monitoring and evaluating progress. This report can build on a considerable body of previous work in this area, including the MARD products and the Mental Health Foundation's inclusion in the NSUN partnership. There are a number of publications on the subject of good practice in involvement, whether it be in organisations, in research or in other activities. (see, for example, Faulkner, 2004).

One approach to the subject is to think of involvement in terms of purpose, presence, process and impact (PPPI). These four headings present a relatively accessible way of describing and monitoring involvement.

- **Purpose:** having a clear purpose for involvement enables everyone to understand their role and avoids the risk of tokenism and involvement for its own sake.
- **Presence:** the number of service users and carers involved; their characteristics in relation to the project/programme (e.g. age, gender, ethnicity, specific (service/diagnosis/treatment) experience, and so on);
- **Process:** at what level in the project/programme are service users and carers involved: what role(s) are they occupying?; how is the process of involvement experienced by all? Is the programme/workstream engaging good practice guidelines (e.g. from MARD) to involve people?
- **Impact:** what impact – if any – are service users or carers having on the programme or workstream?

### **Purpose**

The purpose of involvement needs to be clearly stated so that service users and carers know what they are getting involved in and why. The overarching purpose might be to increase the influence of service users and carers in NMHDU's work programmes, and beyond: in improving and developing services and to build capacity to support involvement beyond NMHDU. However, each individual work programme, project and role will need to have its own clearly articulated purpose for involving service users and carers.

Explicit clarification of the purpose of involvement can help to identify roles and potential activities for service users and carers as well as an appropriate and transparent recruitment process. If, for example, it is required that a service user or carer sit on a board to represent the views of others, then they will need to be recruited from a wider group or network, and time will need to be given for them to consult with their wider constituency in between meetings.

## **Presence**

Service user and carer involvement has taken and continues to take a number of different forms within the NMH DU programmes and workstreams, both individually and collectively. A number of different roles have emerged for the involved service user or carer. People have been 'ambassadors' for some programmes, been employed as Expert Advisors, attended as members of reference groups or on programme boards and engaged in a number of different activities depending on the nature of the work.

Several of these roles and positions have worked well in different programmes; having a clear purpose for involvement can make the role(s) easier to identify. This is demonstrated by both the development of the role and the preparation for it (e.g. a process for recruitment, role descriptions). The role with a purpose might be one of the following (although overlap is clearly possible):

- **Ambassador** (i.e. committed to the ethos of the workstream or programme, promoting it, spreading the word, engaging others)
- **'Critical friend'** (i.e. both programme and involved users/carers able and prepared to engage in meaningful debate to reach a satisfactory negotiation of work programme/policy/delivery)
- **Delivery agent** (i.e. working directly with programme members to deliver the work of the programme)
- **Co-worker** (employed as a member of the team to deliver the work)

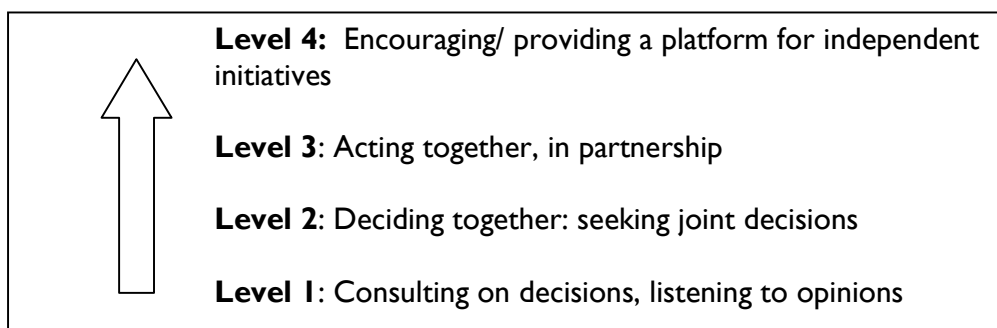
Examples of these include: the Shift programme and its team of 14 Expert Advisors (who have covered all of these roles, with an emphasis latterly on being delivery agents); team member for the IMHA workstream (employed as an equal member of the team to deliver the training); the DRE/Equalities Ambassadors programme.

## **Process**

The key issues that fall under this heading are as follows:

- Clear communications
- Support for involvement:
  - Administrative
  - Supervisory
  - Emotional
- Training to enable equitable involvement
- Payment of fees and expenses
- Feedback to all who have been involved about the results of that involvement
- Provide a range of different activities or ways of being involved in order to attract a wider range of service users and carers
- Flexibility – to enable people to take advantage of different opportunities and to move in and out of involvement when they wish to or need to.

One way of describing the process is to look at the levels of involvement as has been conceived of elsewhere (based loosely on Arnstein's ladder of participation):



## **Impact**

This is the hardest element of involvement to establish, but also the most important. The questions to address here are: how do we know that service users or carers have been involved in a programme of piece of work? What difference have they made? Is the difference positive or negative? Has involvement strengthened the programme, improved its relevance to or influence on local services?

Impact might usefully be explored in the following areas:

- **Ethos:** has the involvement of service users and/or carers influenced the ethos and values of the project or programme: made it more acceptable and accessible to services and people locally? ... made it more inclusive of diverse and marginalised groups? ...
- **Policy and Planning:** has the involvement of service users and/or carers influenced the development of policy or the planning of the project (at governance level)? Is it possible to pinpoint specific decisions or directions taken by the programme that were influenced by service users and/or carers? Have specific developments been designed or led exclusively by service users or carers?
- **Delivery:** has the delivery of the project been influenced by service users or carers? Have service users or carers been involved in delivering alongside other team members (e.g. training, presentations at conferences)?
- **Outcomes and outputs:** have the outcomes of the programme been influenced by service users or carers? Has the programme as a whole had a different impact than it might have done as a result of the involvement of service users and/or carers? Have any of the materials produced been designed or contributed to by service users or carers?

## **VII Recommendations**

Central to the recommendations, in the view of many people consulted for this work, is the need to act – and to cease writing reports on involvement! In a world that is increasingly talking of ‘co-production’ rather than involvement, there is a pressing need to stop seeing involvement as a small part of the whole – but rather to see it as an equal part of the whole. The recommendations are structured around the PPPI baseline standards, as follows:

### **Purpose:**

We recommend that

- each individual work programme, workstream and project has its own clearly articulated purpose for involving service users and carers; and that:
- this purpose is clearly communicated to all concerned at the start of any involvement activity.

### **Presence:**

- We recommend that each programme and workstream set aside resources for the involvement of service users and carers, and that the use of these resources be audited and demonstrated on an annual basis.
- We recommend that each programme and workstream consider involving service users and carers in the following ways:
  - Governance *Critical friend*
  - Staffing (as employee, consultant) *Co-worker/delivery agent*
  - Quality assurance (e.g. advisory or reference groups, focus groups) *Critical friend*
  - Networking and dissemination *Ambassador*
  - As potential contractors for commissioned pieces of work *delivery agent*
- We recommend that each programme and workstream seek to include service users and carers from BME communities as a priority; suggestions for facilitating this include:
  - Ensure that there is a range of different methods for becoming involved;
  - Engage with networks such as the DRE/Equalities Ambassadors, the Afiya Trust and the Catchafiya network.
  - Learn from other programmes – e.g. DRE Ambassadors programme, Shift

### **Process:**

- We recommend that NMH DU programme & workstream leads refer to MARD guidance on good practice with respect to the *process* of involvement, paying attention to:

- Establishing clear and transparent **recruitment procedures** for any involvement activity: to include clear articulation of the purpose of involvement and role descriptions for positions available;
- **Communicating clearly and openly** throughout the work of the programme/worksteam, to ensure that service users and carers are as informed as everyone who is involved in the work.
- **Paying** people fees and expenses in accordance with the guidelines;
- **Supporting** service users and carers adequately in relation to their emotional, administrative and work-related needs;
- Ensuring that **information** distributed to service users and carers is timely, clear and accessible, and jargon-free where possible. Note: this is particularly important where high-level / governance meetings are concerned.
- Providing **training** where it is needed, to enable service users and carers to participate on equal grounds;
- Providing **feedback** to service users and carers about the impact of their involvement.

### **Impact:**

We recommend that:

- All programmes and workstreams monitor and evaluate the impact of the involvement of service users and carers on a regular basis, *and that they...*
- Assess the impact of involvement in relation to the following headings (see VI Baseline standards):
  - Ethos
  - Policy and Planning
  - Delivery
  - Outcomes and outputs
- NMHDU evaluates the impact of the involvement of service users and carers across all programmes and workstreams.

*Please note: resources to assist with evaluation are listed in the table overleaf*

### **MARD products:**

- We recommend that NMHDU commission a piece of work to:
  - Design a means of navigating through the MARD products (perhaps based on a FAQs approach);
  - Revise the payments policy in line with current welfare benefits and employment law;
  - Re-brand the products for NMHDU and re-launch them with access via the NSUN website as well as NMHDU website.

**The Involvement Monitoring Table overleaf is proposed as a means of assisting with monitoring progress towards these recommendations.**

## Involvement Monitoring Table

|                 | <b>Baseline standards</b>  | <b>Assess gaps →</b> | <b>Set objectives</b> | <b>Monitor progress</b> | <b>Resources to aid monitoring</b>  |
|-----------------|--|----------------------|-----------------------|-------------------------|---|
| <b>Purpose</b>  | <ul style="list-style-type: none"> <li>• A clear statement of purpose is applied to each and every involvement activity</li> <li>• This purpose has been communicated to everyone involved in the work (not only service users and carers).</li> </ul>   |                      |                       |                         | MARD resources: <ul style="list-style-type: none"> <li>• Operational policy;</li> <li>• Induction package;</li> <li>• Communications strategy;</li> </ul>   |
| <b>Presence</b> | <ul style="list-style-type: none"> <li>• There are service users and carers involved at all levels within the programme:               <ul style="list-style-type: none"> <li>○ Governance</li> <li>○ Quality assurance</li> <li>○ Staffing / project delivery</li> <li>○ Other...</li> </ul> </li> <li>• There are service users and carers from relevant BME communities involved in the programme.</li> </ul> |                      |                       |                         | <ul style="list-style-type: none"> <li>• MARD Operational policy;</li> <li>• MARD Minimum standards and recommendations supporting the involvement of all diverse and marginalised groups, their service users and their carers</li> <li>• Cross-programme learning: refer to good practice resources in this document</li> </ul> |
| <b>Process</b>  | Good practice guidelines have been implemented concerning: <ul style="list-style-type: none"> <li>• Recruitment</li> <li>• Communications</li> <li>• Information</li> <li>• Support</li> <li>• Training</li> <li>• Payments</li> <li>• Feedback</li> </ul>   |                      |                       |                         | MARD resources: <ul style="list-style-type: none"> <li>• Good practice guidance;</li> <li>• Payment guidelines;</li> <li>• Involvement passport;</li> <li>• Training packages for staff;</li> <li>• Communications strategy;</li> <li>• Leadership training packages – for service users and carers</li> </ul>                    |

|                      |  |  |  |  |   |
|----------------------|--|--|--|--|---|
| <p><b>Impact</b></p> | <ul style="list-style-type: none"> <li>• Ethos</li> <li>• Policy and Planning</li> <li>• Delivery</li> <li>• Outcomes and outputs</li> </ul> |  |  |  | <p>1. MARD tools for monitoring and evaluation;</p> <p>2. Improvement Leaders' Guide:<br/> <b>Evaluating improvement:</b><br/> <i>General improvement skills</i><br/>                     NHS Institute for Innovation and Improvement (2005)</p> |
|----------------------|--|--|--|--|---|

## **APPENDIX A : RECOMMENDATIONS FROM HASCAS (2005)**

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.

| <b>APPENDIX B</b>                                |  |  |  |
|--|--|--|--|
| <b>Contacts made during Consultation Process</b> |  |  |  |
| <b>Programme</b>                                 | <b>Contacts</b>  | <b>Record of contact</b>                                 | <b>Service user / carer contacts</b>   |
| <b>General</b>                                   | Oversight board - Ian McPherson<br>Jim Symington 0781 331 9362<br><a href="mailto:jim.symington@nmhdu.org.uk">jim.symington@nmhdu.org.uk</a>   | 21-9-09 ✓<br>21-9-09 ✓                                   |  |
| <b>MARD</b>                                      | Liam Gilfellon (as above)  | Meeting 26/10 ✓  | Laurie Bryant, Lu Duhig, and many others involved in each product in each region...  |
| <b>IAPT</b>                                      | James Seward (Lead)<br><br>Kevin Jarman – sent csip documents via SY   | Emailed<br><br>LB/LD<br>22-9-09 ✓                        | Laurie Bryant (service user)<br>Lu Duhig (carer)<br><i>Interviewed</i><br>There are others involved from NIMHE/CSIP work<br>Paul Johnson (below), also Fenella Lemonsky involved on the 'New Ways of Working' for psychological<br><a href="mailto:flemonsky@aol.com">flemonsky@aol.com</a>  |
|  | Liam Gilfellon (NE region) <i>also MARD former project manager</i><br><a href="mailto:Liam.gilfellon@nhs.net">Liam.gilfellon@nhs.net</a> 07971 86776   | Tel 25-9-09 / meeting 26-10-09 ✓                         | Paul Johnson – Involvement lead at NE MHDU   |
| <b>Social Inclusion and Social Justice PSA16</b> | Paddy Cooney<br><a href="mailto:paddy.cooney@swdc.org.uk">paddy.cooney@swdc.org.uk</a><br>Zoe Robinson   | ✓ via 27/10<br><br>28/10 ✓                               | (as NSIP – involved 4 expert advisors from SHIP)<br><b>Rosemary Wilson, Sona Peskin, Diane Hackworth</b> reference group. See NSIP report for further details  |
|  | Shift programme: Gary Hogman<br><a href="mailto:gary.hogman@nmhdu.org.uk">gary.hogman@nmhdu.org.uk</a><br>07789922314<br><i>has links with Equalities prog (Melba)</i>   | Emailed GH<br>28/09/09 / GH meeting 30/9 ✓<br>FS 19/10 ✓ | <i>Shift: 14 expert advisors inc:</i> Fran Singer 07879<br><a href="mailto:frances.singer@gmail.com">frances.singer@gmail.com</a> and Hanif Bobat 079<br><i>(contact Gary for the others' contact details)</i>   |
| <b>Equalities</b>                                | Melba Wilson<br><br>Julie Jay Charles – Ambassadors programme *  | Meeting 19/10 ✓<br><br>Tel interview 11/10 ✓             | Julie J Charles – Lead Ambassador<br>0207 474 9812 office / 07932655866 mobile<br><a href="mailto:juliej.charles@equalitiesnational.org.uk">juliej.charles@equalitiesnational.org.uk</a><br>c.32 ambassadors recruited, 2-3 in each region.<br>of the ambassadors  |
| <b>Pathways to Care</b>                          | <b>Jim Symington – see above</b><br><ul style="list-style-type: none"> <li>Standards for Children and Young People - <a href="#">Kathryn Pugh</a></li> <li>Dual Diagnosis - <a href="#">Tom Dodd</a> / <a href="#">Ann Gorry</a></li> <li>Violence and Abuse - <a href="#">Liz Mayne</a></li> </ul>  | ✓ as above<br><br><i>Emailed most of these on 29/9</i>   | DD: qu're filled in by email (Ann Gorry) – no contact  |
|  | <b>Personality Disorder - Nick Benefield</b><br>Clare Stafford (Community)<br><a href="mailto:clare.stafford@dh.gsi.gov.uk">clare.stafford@dh.gsi.gov.uk</a><br>Rex Haigh (Clinical advisor)<br><a href="mailto:rexhaigh@nhs.net">rexhaigh@nhs.net</a><br>Cathy James (Children & YP)<br><a href="mailto:cathy.james@dh.gsi.gov.uk">cathy.james@dh.gsi.gov.uk</a><br>Nick Joseph (CJS)<br><a href="mailto:nick.joseph@noms.gsi.gov.uk">nick.joseph@noms.gsi.gov.uk</a> | Questionnaire returned                                   | Kath Lovell, London <a href="mailto:kathlovel@mac.com">kathlovel@mac.com</a><br>Sue Imlack, W Midlands <a href="mailto:sueimlack@hotmail.com">sueimlack@hotmail.com</a><br>Helen den Hartog, Thames Valley <a href="mailto:helenlegg@bt.com">helenlegg@bt.com</a><br>Emma [need to confirm details], Kent<br>Lesley Shilling, Leeds <a href="mailto:lesleyshilling@yahoo.co.uk">lesleyshilling@yahoo.co.uk</a><br>Andy Brooker, Tunbridge Wells <a href="mailto:andy.23@talktalk.com">andy.23@talktalk.com</a><br>Kati Turner, Chair, Emergence (previously 'Bored Plus') <a href="mailto:kati.janeturner@aol.com">kati.janeturner@aol.com</a> |

## Final draft

|                      |  |                         |   |
|----------------------|--|-------------------------|---|
|                      | Implementation of the MHA - <a href="#">Malcolm King</a>                     | Malcolm King<br>15/10 ✓ | Sarah Dewey / SUCs group – MHA implementation<br><a href="mailto:sarahdewey.work@virgin.net">sarahdewey.work@virgin.net</a> <a href="mailto:andrewandvalbail">andrewandvalbail</a><br>Rampaul Chamba <a href="mailto:r.chamba@blueyonder.co.uk">r.chamba@blueyonder.co.uk</a><br><a href="mailto:priscilla.brown@ntlworld.com">priscilla.brown@ntlworld.com</a> ; Christine Halliday<br><a href="mailto:christine.halliday@blueyonder.co.uk">christine.halliday@blueyonder.co.uk</a> ; Nick Nalla<br><a href="mailto:nicknalladorai@hotmail.co.uk">nicknalladorai@hotmail.co.uk</a> |
|                      | Early Intervention - <a href="#">David Shiers</a> / <a href="#">Jo Smith</a> | DS 28/10 ✓              | El prog<br>Sheena Foster <a href="mailto:sheenafooster@btinternet.com">sheenafooster@btinternet.com</a><br>Valerie Minns <a href="mailto:valerie.minns@rethink.org">valerie.minns@rethink.org</a><br>Fran Singer <a href="mailto:frances.singer@googlemail.com">frances.singer@googlemail.com</a><br>Maurice Vaillancourt <a href="mailto:mo@pare.org.uk">mo@pare.org.uk</a><br><a href="mailto:maurice.vaillancourt@academyformentalwealth.com">maurice.vaillancourt@academyformentalwealth.com</a><br>Rory Byrne <a href="mailto:theburn@hotmail.com">theburn@hotmail.com</a>     |
|                      | Acute Care - <a href="#">Yvonne Stoddart</a>                                 | ✓ tel.call 26/10        | Marion Janner – Star Wards. 07932 696083<br>Lynne Gibson <a href="mailto:lyndylou1964@hotmail.com">lyndylou1964@hotmail.com</a> 0754<br>Carers: Alan Worthington <a href="mailto:danda08@talktalk.net">danda08@talktalk.net</a><br>Anthony Rivett 201 Fountains Rd, Ipswich IP2 9   |
| <b>Wellbeing</b>     | Gregor Henderson   | 12/10/09 ✓ VF           |   |
| <b>Commissioning</b> | Kieron Murphy  | Meeting 6/10 ✓          |   |

## APPENDIX C

### THE MAKING A REAL DIFFERENCE PRODUCTS

#### I Policies and Procedures

These outline the overarching corporate commitments to involvement.

- **A NIMHE corporate policy and vision statement** on Service User and Carer involvement: developed in response to the perception that NIMHE did not have a clear commitment to involvement that was consistent throughout the organisation
- **An operational policy** ensuring involvement is sought in all work programmes This outlines the expectations that NIMHE has for each and every employee, and explains in detail exactly how;
  - Involvement will be sought in all work programmes
    - All work will follow the principles of good practice
  - All work will demonstrate respect for all participants, and promote their dignity, wellbeing and effectiveness

#### II Guidelines, Recommendations and Minimum Standards

The policies and procedures developed by the Making a Real Difference Project will be supported and informed by the following;

- **Good practice guidance** for all programme leads to employ when involving service users and carers; a resource for anyone to use as a tool to improve involvement within their current and future work practice.
- **Minimum standards and recommendations supporting the involvement of all diverse and marginalised groups, their service users and their carers.** These minimum standards were developed in response to issues highlighted within the Making a Real Difference report outlining how poorly people from groups outside of those of working age adults with experience of accessing secondary care mental health services, are engaged in the NIMHE programme and its activities. The Minimum Standards are a set of overarching principles which will:
  - Apply to all NIMHE programmes and activities at national or regional level
  - Acknowledge the rights of all service users and carers to work with NIMHE, whatever their background
  - Be part of a culture change within NIMHE towards a more people focused approach, built on mutual respect
- **Good practice guidelines for commissioners** regarding how they can support involvement at a local level: guidelines for Regional Development Centre (RDC) staff to share with Commissioners to enable them to focus on how they support existing and commission new service user and carer led services in the area.
- **Involvement leadership - training recommendations.** This report is a compilation of positive training and support practice already delivered within NIMHE via the existing leadership programmes. It also looks beyond NIMHE for other similar examples of training

courses and support systems for service user and carer leadership. It also sets out a model of involvement, detailing the different levels of involvement within the organisation.

- **Guidelines regarding payment for involvement:** to establish some consistency in the way that service users and carers are rewarded and reimbursed for their participation in NIMHE.

### **III Systems**

The Making a Real Difference project has developed some working systems which will enable the guidelines, recommendations and minimum standards to be implemented, ensuring that we can demonstrate NIMHE's commitment to the policies and procedures developed. These systems are outlined below;

- **A national communications strategy** to support involvement including innovative methods of accessing and commenting on information. The strategy will ensure that NIMHE is clear about its function, and can communicate this effectively with all of its partners in relation to involvement. It will also outline how feedback will be received by the organization and outline how any resulting actions/outcomes will be communicated back to the relevant parties.
- **Induction packages for new employees.** This will develop the understanding of the responsibility placed upon all staff to effectively involve service user and carers in all of their work. It is imperative that this is made clear from the beginning of employment. The induction pack will be a self directed work book which will help new staff to develop these skills and awareness of their responsibility.
- **Training packages for existing staff** to support awareness sessions regarding the importance of involvement. As above there is a commitment to develop all staff to effectively involve service user and carers in all work undertaken within NIMHE. The training pack will outline training tools, exercises and methods to enable trainers to hold regular involvement awareness training with all existing NIMHE staff.
- **A network for people with experience of using mental health services** to provide expertise to NIMHE at a national level The network will give people with experience of using mental health services the opportunity to represent the expertise and views of their peers within their regional networks or groups on any national work programmes and the NIMHE Board.
- **A network for people with experience of supporting friends and family** who have in the past or are currently using mental health services to provide expertise to NIMHE at a national level This network will give people with experience of supporting and caring for people using mental health services the opportunity to represent the expertise and views of their peers within their regional networks or groups on any national work programmes and the NIMHE Board.
- **Methods and tools that will enable the monitoring and evaluation** of involvement across 3 key areas.;
  - i. Accessing involvement including selection of people to become involved.
  - ii. Experience of being involved
  - iii. Impact and outcomes of involvement

- **The Involvement Passport.** The content of the passport will provide a means of operationalising all of the products from the Making a Real Difference Project. It will provide clear information about what a person is involved in, why their involvement is important, who the relevant people within the project are and what everyone can expect during the period of involvement. This will enable the levels and effectiveness of involvement to be easily monitored.

*All of the documents outlined above have been developed in full partnership with a variety of stakeholders across the regions. All of the documents were widely distributed for consultation before being signed off by the national Making a Real Difference Steering group.*

## **APPENDIX D**

### **List of Resources (for review/amendment re: carers)**

Badham, B and Wade H. (2008) *Hear by Right: standards framework for the participation of children and young people*. revised edition 2008. The National Youth Agency. <http://hbr.nya.org.uk/>

Breast Cancer Care *User Involvement Strategy 2007-2010*. (Good example of an organisational strategy)

Campbell, P. (2005) 'Harnessing our energy' chapter in *Beyond the Water Towers* (see below). Sainsbury Centre for Mental Health.  
[www.scmh.org.uk/publications/beyond\\_the\\_water\\_towers.aspx?ID=411](http://www.scmh.org.uk/publications/beyond_the_water_towers.aspx?ID=411)

Campbell, P (2005) "From Little Acorns - The mental health service user movement" in Sainsbury Centre for Mental Health (2005) "*Beyond the Water Towers - The unfinished revolution in mental health services 1985-2005*". London: The Sainsbury Centre for Mental Health.  
[www.scmh.org.uk/pdfs/mental+health+service+user+movement.pdf](http://www.scmh.org.uk/pdfs/mental+health+service+user+movement.pdf)

Crawford, MJ, Rutter, D, Manley, C, Bhui, K, Weaver, T, Fulop, N and Tyrer, N (2001). *User Involvement in the Planning and Delivery of Mental Health Services*. Report to London Region NHSE.

Crawford, MJ, Rutter D, Thelwall S. (2003) *User involvement in change management: A Review of the literature*. Report to NHS Service Delivery and Organisation Research and Development. [www.sdo.lshtm.ac.uk/changemanagement.htm](http://www.sdo.lshtm.ac.uk/changemanagement.htm)

Department of Health/CSIP (2006) *Reward and recognition: the principles and practice of service user payment and reimbursement in health and social care* (second edition).

Department of Health (2001). *Research Governance Framework for Health and Social Care*. London: Department of Health.

Department of Health (1999) *National Service Framework for Mental Health: Modern Standards and Service Models*. London: Dept of Health.

Faulkner A & Morris B. (2003) *Expert Paper on User Involvement in Forensic Mental Health Research and Development*. National Programme on Forensic Mental Health Research and Development. (copies available from the author: [alison.faulkner2@btinternet.com](mailto:alison.faulkner2@btinternet.com))

Faulkner, A. (2004) *The Ethics of Survivor Research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Bristol: Policy Press on behalf of the Joseph Rowntree Foundation.

Faulkner, A. (2004) *Capturing the Experiences of those Involved in the TRUE Project: a story of colliding worlds*. INVOLVE. [www.invo.org.uk/pdfs/Colliding%20Worlds.pdf](http://www.invo.org.uk/pdfs/Colliding%20Worlds.pdf)

Hanley B & Staley K. *User and Carer Involvement: Sharing our Experience*. LMCA: London. [www.twocanassociates.co.uk/pubs.htm](http://www.twocanassociates.co.uk/pubs.htm) .

Hanley B & Staley K. *User and Carer Involvement: A Good Practice Guide*. LMCA: London. [www.twocanassociates.co.uk/pubs.htm](http://www.twocanassociates.co.uk/pubs.htm)

Hanley B. et al (2004) *Involving the public in NHS, public health and social care research: Briefing notes for researchers*. (second edition edited by Roger Steel) INVOLVE. [www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf](http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf)

HASCAS Making a Real Difference: *Strengthening Service User and Carer Involvement in NIMHE*. Final report April 2005. <http://www.nimhe.csip.org.uk/silo/files/final-making-a-real-difference-report.pdf>

Kalathil, J. (2008) *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. National Service User Network in collaboration with Catch-a-Fiya. [www.nsun.org.uk/WebPageFiles/65/NSUN\\_Report.pdf](http://www.nsun.org.uk/WebPageFiles/65/NSUN_Report.pdf)

NHS Institute for Innovation and Improvement (2005): *Improvement Leaders' Guide Evaluating improvement: **General improvement skills***. Gateway ref: 5667 [www.institute.nhs.uk](http://www.institute.nhs.uk)

NHS Wales. *Signposts: A practical guide to patient and public involvement in Wales*. (2001). London: Office for Public Management, Cardiff: National Assembly for Wales.

NHS Wales. *Signposts Two: Putting public and patient involvement into practice*. (2003) London: Office for Public Management, Cardiff: National Assembly for Wales.

NIMHE/CSIP (2006) *Valuing Involvement: Strengthening Service User and Carer Involvement in NIMHE: Good Practice Guidelines for involving mental health service users and carers*.

NIMHE/CSIP (2008) *Valuing Involvement: Making a Real Difference Strengthening Service User and Carer Involvement in NIMHE and CSIP: Payment and Reimbursement Policy Guidance*.

Robson P, Begum N and Locke M. (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*. York: The Policy Press in association with the Joseph Rowntree Foundation. [www.policypress.org.uk/catalog/product\\_info.php?cPath=10033&products\\_id=464](http://www.policypress.org.uk/catalog/product_info.php?cPath=10033&products_id=464)

Rose D, Fleischmann P, Tonkiss F, Campbell P and Wykes T. (2003) *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature Report to NHS SDO R&D programme*. [www.sdo.lshtm.ac.uk/changemanagement.htm](http://www.sdo.lshtm.ac.uk/changemanagement.htm)

Rose, D (2001). *Users' Voices: The Perspectives of Mental Health Service Users on Community and Hospital Care*. London: The Sainsbury Centre for Mental Health.

Scottish Poverty Information Unit. 2007 *Empowerment, Employability and Service User Involvement: Literature Review*. [www.serviceuser.org/show.php?contentid=55](http://www.serviceuser.org/show.php?contentid=55)

Simpson, E. & House, A.O. (2002) Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*, 325, 1265 (30 November).

Staley K & Hanley B. *User and Carer Involvement: How to Develop a Strategy*. LMCA: London. <http://www.twocanassociates.co.uk/pubs.htm> .

SURGE (Service User Research Group England) (2005) *Guidance for Good Practice: Service user involvement in the UK Mental Health Research Network*. London: UK MHRN. <http://www.mhrn.info/index/ppi/SUR/good-practice-guidance.html>

Time to Change: resources at <http://www.time-to-change.org.uk/>

Wallcraft, J., Read, J. & Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*. London: The Sainsbury Centre for Mental Health. [http://www.scmh.org.uk/publications/on\\_our\\_own\\_terms.aspx?ID=376](http://www.scmh.org.uk/publications/on_our_own_terms.aspx?ID=376)

Welsh Assembly Government. *Stronger in partnership: involving service users and carers in the design, planning, delivery and evaluation of mental health services in Wales: policy implementation guidance* Cardiff: Wales. Welsh Assembly Government, 2004.

Welsh Assembly Government. *Stronger in Partnership 2: Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales* Cardiff, Wales: Welsh Assembly Government, 2008. <http://www.wales.nhs.uk/documents/strongerpartner2e%5BI%5D.pdf>