

Care Services Improvement Partnership **CSIP**

National Institute for
Mental Health in England



Making a Real Difference

**Strengthening Service User and
Carer Involvement in NIMHE**

Final Project Report;

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Executive Summary

The Making a Real Difference report was commissioned by the NIMHE National and Regional Directors in June 2004, to develop recommendations for improving Service User and Carer involvement throughout the NIMHE programme. The resulting report was fully endorsed by the Directors and CSIP North East Yorkshire and Humber were tasked with delivering on the recommendations outlined within the report.

The end of the national Making a Real Difference project in no way marks an end to the work to strengthen involvement in the NIMHE programme, but heralds the beginning of a long but significant period of change in the way we all work within the NIMHE programme and the culture that exists within the organisation.

As a result of the Making a Real Difference project, the systems, guidelines, policies and procedures developed in partnership with our stakeholders, will enable the NIMHE programme to develop a systematic approach to involvement. This will ensure that service improvement is being led by example, affording us to utilise not only the expertise of the NIMHE staff teams, but also the huge potential expertise held by people using mental health services and those caring for them. This will help us to fulfil the principles set out in the White Paper: Our Health, Our Care, Our Say - a new direction for community services; which states that "change is to be driven, not centrally, but in each community by the people who use services and by the professionals who provide them." (Tony Blair –January 2006).

The end of this project comes at a time when the future of the NIMHE programme and CSIP is unclear. What is clear is that this project has produced a comprehensive set of minimum standards which will lay the foundations for effective service user and carer involvement, to be built on in whatever structure follows.

THE MAKING A REAL DIFFERENCE PRODUCTS

Throughout the Making a Real Difference project, the policies, guidelines and systems which have been developed and delivered by the work groups were referred to as "products". This term has proved unpopular during the project, however whilst we have searched for a more friendly description, it seems that "products" remains the most appropriate way to describe the collective term for all of the policies, guidelines and systems produced by the work groups. We outline below the products developed under the three headings: 1. policies and procedures, 2. guidelines, recommendations and minimum standards and 3. systems.

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

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**
This guidance has been developed to inform people about best practice, and to grow and nurture involvement within NIMHE and across the health and social care communities. It is 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**

These good practice guidelines were developed in direct response to recommendation 5 within the Making a Real Difference report;
“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 and service user and carer groups”
They provide 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 CSIP/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 for Regional Development Centres regarding payment for involvement**

One of the key areas the Making a Real Difference report defined was the development of national payments policy guidance. This would establish some consistency in the way that service users and carers are rewarded and reimbursed for their participation in NIMHE.
The document has been designed to deliver that consistency, by providing a template from which CSIP Development Centres and NIMHE national programmes are able to produce procedures tailored to their own needs.

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 Development Centre's to monitor and evaluate involvement across 3 key areas.**

These tools will allow monitoring and evaluation of performance regarding involvement in the following three 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.

Chapter 1 Introduction – Setting the Scene

1.1 NIMHE Mission on Involvement

In 2003, NIMHE's commitment to involvement was;

“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”. 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”.*

This commitment made by NIMHE set 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 had evolved differently within different programmes and in the eight regional development centres (RDC's).

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 aimed to strengthen service user and carer involvement and move closer to NIMHE's stated commitment.

In June 2004 NIMHE commissioned the Health and Social Care Advisory Service (HASCAS), and their team, predominantly made up of people who had experience of using services or caring for someone who had used services, to undertake a comprehensive review of service user and carer involvement within NIMHE.

In April 2005 HASCAS published the findings of this comprehensive review in the **“Making a Real Difference – Strengthening Service User and Carer Involvement in NIMHE”** report.

1.2 Report Aims

HASCAS developed the report by identifying four aims for their project:

- 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 delivery of national work programmes
 - the regional development centres (RDCs)

- the 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.

1.3 How the information was gathered

In order to meet these aims different methods were used. In particular the HASCAS team 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 people with personal experience of managing mental health problems who do not identify themselves as service users and carers.

In summary, the process 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.
4. Focused interviews with different stakeholders, both internal and external to NIMHE as follows (the numbers in brackets indicate the amount of interviews undertaken):
 - 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)
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 involving 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.
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.

1.4 Report Findings

The main findings of the Making a Real Difference report found that at the time of publication ;

- NIMHE was a relatively young organisation, which was developing a range of ways that service users and carers can become involved.
- There were good examples both at a national and a regional level of service user and carer involvement in NIMHE.
- While it was true to say that some service users and carers were able to express their views and influence NIMHE, this was not the case for all. In particular the involvement of the following groups of people tended 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 was clear that service users were better involved than carers.
- The overall assessment of service user and carer involvement suggested that they felt they had little influence over NIMHE, neither on setting the agenda nor in making decisions. The majority of people wanted to see the situation changed for the better.

- At a national level service users and carers could be, and were involved in national programmes including research. However, while there was a national service user and carers group - the Experts by Experience group - its purpose was unclear and it was not well resourced. Nor did 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, where there was significant investment in support of it. Despite this, issues remained 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 was recognised that NIMHE needed to operate differently if it was going to involve a greater degree of diversity amongst service users and carers. This would involve going out to where people were, developing different ways of working and addressing the barriers which currently restricted involvement, which included tackling different forms of discrimination.
- It was clear that service users and carers and staff working for NIMHE wanted to see involvement strengthened.
- The first step to strengthening involvement was ensuring that there was the organisational commitment to do so; this meant 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 needed to be clear about the purpose of being involved, provide more information, pay particular attention to strengthening diversity and develop representative structures.
- NIMHE also needed to ensure that there were clear processes for recruitment, induction and training and practical support available to facilitate involvement.

1.5 Framework for Involvement

The Making a Real Difference report then provided a proposed framework which built on the findings from the HASCAS team. There are four levels to this framework;

- 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.

1.6 Implementing the Framework

The report set out seven critical challenges which NIMHE needed to tackle in order to achieve successful implementation of the framework;

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.

The report also 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.

To assist NIMHE in successfully overcoming the challenges it highlighted, the report made 20 recommendations.

1.7 Making a Real Difference 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 organizational 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 a template outlined in section 4.3 of the report 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 .

1.8 The Next Steps

The report summarised the next steps for NIMHE and set out four key developments that would need to be undertaken to begin to achieve the recommendations made;

- 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 2 Project Approach

2.1 Project Management

After gaining receipt of the final Making a Real Difference Report, it was agreed by the NIMHE Executive Directors that the NIMHE North East, Yorkshire and Humber RDC would be asked to manage the development and implementation of the Making a Real Difference Project.

A project director was recruited and subsequently a project manager appointed to develop a detailed implementation plan and undertake the day to day management of the project.

A project steering group was appointed which including members of the Experts by Experience group, whom the report had identified as being key to informing the process during this period of transition from the current involvement arrangements at national level to the recommended independent democratic networks which would need to be developed. Other members of the steering group included, CSIP Service User and Carer Leads, a CSIP director, experts in delivering services to older people and younger people, a representative from a voluntary sector coalition (representing over 50 organisations), a CSIP Race Equality Lead, a national service user and carer service improvement expert and an external consultant.

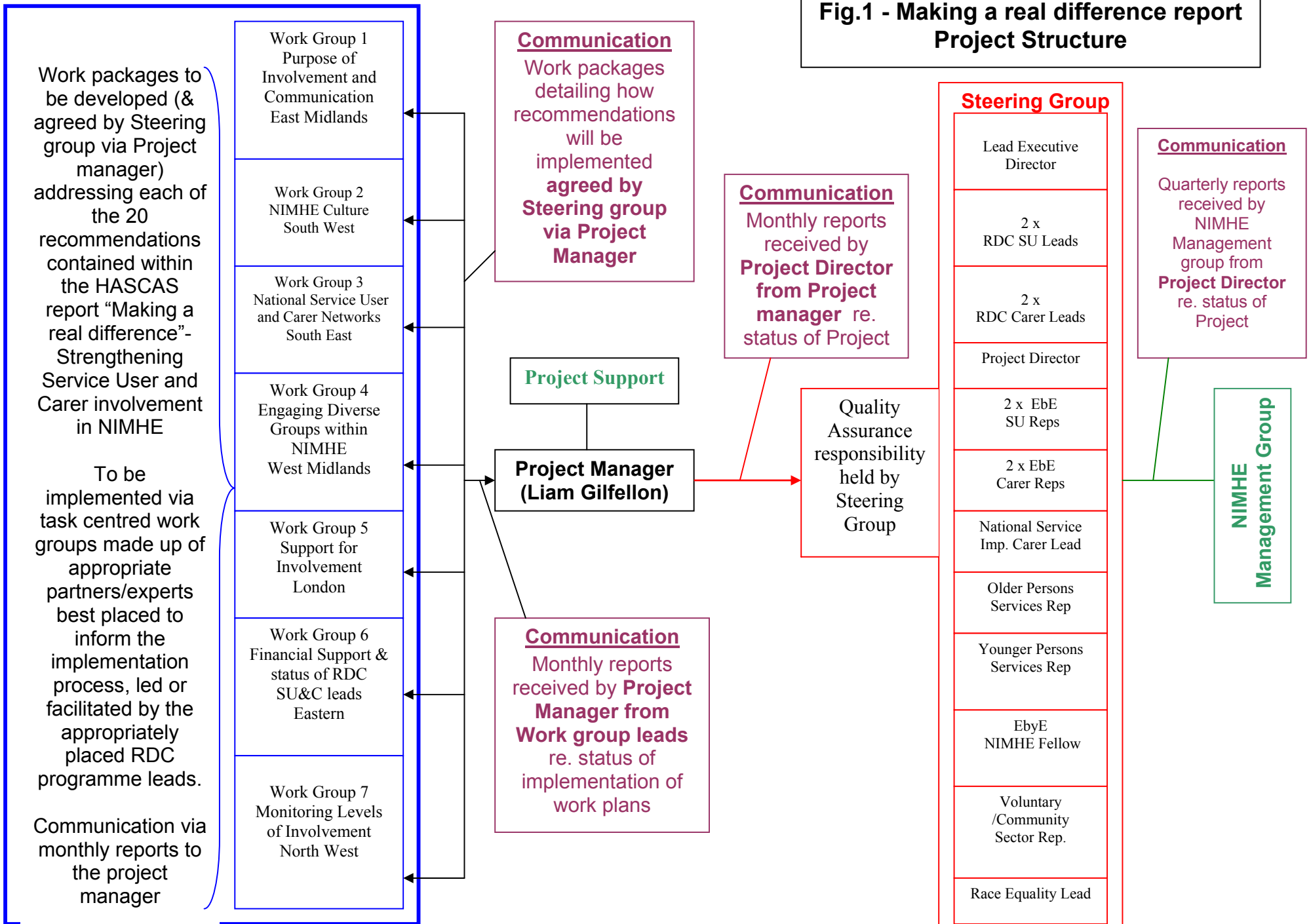
The project manager proposed that a formal project management methodology be used to undertake this important project, and that PRINCE2 (PRojects IN Controlled Environments 2) be utilised. This enabled the project to be developed, delivered and monitored in a structured way.

2.2 Project Structure

To ensure that the project was developed in a clear and transparent way a diagram of the project structure was developed, showing the lines of accountability and communication structures.

This structure was developed using methods suggested by PRINCE 2 methodologies, and is shown as fig. 1

Fig.1 - Making a real difference report Project Structure



2.3 Project Plan

It was identified within the report that to implement the recommendations and work toward implementing the involvement framework as is described in the Making a Real Difference report, “a clear and costed timetable for implementing the proposals needs to be developed”.

An overarching project plan was developed detailing how the recommendations would be taken forward and grouping them into 7 deliverable groups, which would need to be delivered to implement the 20 recommendations in the report.

The responsibility for the delivery of each work group was allocated to a lead CSIP Development Centre.

The following table sets out the work group breakdown, detailing which recommendations they would deliver, the overarching principles of the work group, and brief explanation and who was responsible for its delivery;

Recommendations	Principle	Explanation	Work Group
Work Group 1 Recommendations 1,2,3&12	Purpose of Involvement and Communication	This refers to the need for NIMHE to be clear about what it does, how it involves people and the acceptance and willingness of all staff to truly place service users and carers at the heart of all they do.	Work Group led by RDC Carer lead from East Midlands
Work Group 2 Recommendations 8,13&16	Culture	Consider how all programme leads will involve SU&C in their work and what training all staff need to enable this.	Work Group led by RDC Inclusion lead from South West
Work Group 3 Recommendations 6,7	National networks and involvement opportunities	NIMHE will need to link local, regional and national networks and provide opps. for representative involvement at a national level. This will be supported by a lead at director level. Network to be commissioned by ind. org. and link with all diverse groups/networks.	Work Group led by RDC Social inclusion and involvement lead from South East
Work Group 4 Recommendations 9 & 10	Engaging Diverse Groups	Need to look at how we broaden involvement with BME, PD,LD, DD, D&A, OP, CYP, linking in with existing networks but providing structure to ensure influence over NIMHE at all levels .	Work Group led by RDC service user and carer lead from West Midlands

Work Group 5 Recommendations 5,11	Support for Involvement	Look at ways of influencing and supporting local networks to flourish and enable informed regional networks to be established. Ensure adequate support is available to appropriately equip SU&C to undertake this role.	Work Group led by RDC service user and lead from London
Work Group 6 Recommendations 14,15,3	Financial Support & status of RDC SU&C leads	Develop guidelines for payment of SU and Carers as well as unifying payment to RDC leads. Also look at status and influence held by SU&C leads at RDC.	Work Group led by RDC Expert by Experience fellow from Eastern
Work Group 7 Recommendations 17	Monitoring of levels of involvement	To monitor the outcomes of SU&C inv. also look at how to employ SU led monitoring techniques for Work programme quality assurance.	Work Group led by RDC service improvement lead from N West
Recommendation 18	Action Plan	Develop initial action plan detailing work groups to take implementation forward, timescales & Comms Plans.	Project Manager, agreed by steering group
Recommendation 19	Safeguard SU&C inv. During switch over to CSIP	Ensure that profile of project influences CSIP development and is safeguarded within NIMHE	Exec Director, with Steering group.
Recommendation 20	Review impact of implementation	Include a post project review plan as each work stream is completed	Project Director

The project plan set out a list of suggested tasks for each work group. The individual work group tasks and products were discussed with each work group lead and more comprehensive and detailed work group project plans were developed in partnership with the project manager. These work group plans set out how each product would be developed in more detail, identifying timescales, responsibilities and methods of consultation.

The decision to give responsibility for the development of the Making a Real Difference Products to task centred work groups within the Regional Development Centres, was in direct response to reflections in the report that there was a positive picture of involvement at a regional level, where it felt that engagement with existing networks was working well.

It was felt that the best way to inform the development of the products was to consult with as many people as possible and this would be best achieved at regional level where the capacity to engage the existing networks was established.

Each work group was overseen by a steering or advisory group, made up of people with experience of mental health problems, friends and families of people with mental health problems and CSIP staff. The approximate make up of these groups is as follow;

Designation	% of steering groups
CSIP Staff	31.5%
People with experience of using mental health services including	40%
People with experience of caring	28.5%

A more detailed breakdown can be seen on the acknowledgements page of each document within the resource pack, where there is also a comprehensive list of the contributors to the work carried out.

The progress of each work group was monitored by the Making a Real Difference Steering group, via regular reporting mechanisms.

2.4 Project Governance and Communication Arrangements

The steering group had responsibility for a number of governance aspects of the project, these included;

- Providing overall direction and management of the project.
- Taking accountability for the success of the project and responsibility and authority for the project within the remit set by the report.
- Approving all major plans and authorising any major deviation from agreed work packages / tasks.
- Holding the authority to sign off each stage of the implementation plan as well as authorising the start of the next stage.
- Ensuring that required resources were committed and arbitrating on any conflicts within the project and negotiating a solution to any problems between the project and any other internal or external bodies.
- Acting as the project's voice, and taking responsibility for the dissemination of information about the project.

Terms of Reference for the steering group were produced which set out each persons responsibility within the group (a copy can be found at mard.csip.org.uk) Role descriptions for steering group members were produced, highlighting their roles and responsibilities. These can be viewed and downloaded at mard.csip.org.uk)

A detailed plan of how the reporting structure would work was highlighted within the project communication plan. This detailed the reporting structures, what information was required and the people with responsibility, as well as informing the project how external communications would be handled and how project issues would be captured.

Details of the reporting structure developed to fulfil the obligations within the communications plan are detailed on figure 1 – Making a Real Difference Report Project Structure (page 20)

Chapter 3 – The Making a Real Difference Products

This chapter of the report details the four elements proposed by the HASCAS team in the Making a Real Difference report, in relation to what an effective involvement framework would look like.

Below each of the four elements is a brief description of the products which were developed to address the challenges of implementing the framework.

3.1 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.”

Taken from the Making a Real Difference Report.

The products developed to create this clear purpose for the involvement of people with experience of mental illness, their friends and families are as follows;

- **A NIMHE corporate Policy and Vision Statement on Service User and Carer Involvement**

This was developed in response to the perception that NIMHE did not have a clear commitment to involvement that was consistent throughout the organisation.

- **A National Communications Strategy to support involvement including innovative methods of accessing and commenting on information**

This 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 organisation and outline how any resulting actions and/or outcomes will be communicated back to the relevant parties.

- **An 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, including the specific information requirements of their role, 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 above products are available to download from www.mard.csip.org.uk They are also detailed on the Making a Real Difference CD ROM and in the Making a Real Difference resource packs.

3.2 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.”

Taken from the Making a Real Difference Report.

The products developed to foster this positive organisational culture are as follows;

- **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.

▪ **Good practice guidance for all programme leads to employ when involving service users and carers**

This guidance has been developed to inform people about best practice, and to grow and nourish involvement within NIMHE and across the health and social care communities. It is a resource for anyone to use as a tool to improve involvement within their current and future work practice.

▪ **Induction Packages for new employees**

This self directed work book will help to develop an 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.

▪ **Training packages for existing staff to support awareness sessions regarding the importance of involvement**

There is a commitment to develop all staff to effectively involve service user and carers in all work undertaken within NIMHE. The training pack outlines the training tools, exercises and methods to enable trainers to hold regular involvement awareness training with all existing NIMHE staff.

▪ **Methods and tools that will enable Development Centres to monitor and evaluate service user and carer involvement across 3 key areas.**

These tools will allow monitoring and evaluation of performance regarding involvement in the following three areas;

- i. accessing involvement including selection of service users and carers
- ii. experience of being involved
- iii. impact and outcomes of involvement

All of the above products are available to download from www.mard.csip.org.uk They are also detailed on the Making a Real Difference CD ROM and in the Making a Real Difference involvement resource pack.

3.3 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.”

Taken from the Making a Real Difference Report.

The products developed to provide the support needed to enable people to get involved with NIMHE are as follows;

- **Involvement Leadership - training recommendations**

This document 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 for Regional Development Centres regarding payment for involvement**

This document has been designed to establish some consistency in the way that service users and carers are rewarded and reimbursed for their participation in NIMHE. It provides a template from which CSIP Development Centres and NIMHE national programmes will be able to produce procedures tailored to their own needs.

- **Minimum standards and recommendations supporting the involvement of people from diverse and marginalised groups.**

These minimum standards were developed in response to issues highlighted within the Making a Real Difference report, outlining how inadequately people from groups outside of those of working age adults with experience of accessing secondary care mental health services, were 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

All of the above products are available to download from www.mard.csip.org.uk
They are also detailed on the Making a Real Difference CD ROM and in the Making a Real Difference involvement resource pack.

3.4 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.”

Taken from the Making a Real Difference Report.

The products developed to enable and nurture these structures for empowerment and representation are as follows;

- **Good practice guidelines for commissioners regarding how they can support involvement at a local level**

These good practice guidelines provide guidance for Regional Development Centre staff to share with commissioners to enable them to focus on how they support existing service user and carer groups, and commission new service user and carer led services in their areas.

This product is available to download from www.mard.csip.org.uk
They are also detailed on the Making a Real Difference CD ROM and in the Making a Real Difference involvement resource pack

- **A network for people with lived experience of mental illness to provide expertise to NIMHE at a national level**

This network will give people with lived experience of mental illness the opportunity to represent the expertise and views of their peers within the existing regional networks. This will provide a democratic and representative viewpoint which will inform and shape any NIMHE work at a national level and on the national NIMHE Management 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 who support, and/or care, for anyone with lived experience of mental illness, the opportunity to represent the expertise and views of their peers within the existing regional networks. This will provide a democratic and representative viewpoint which will inform and shape any NIMHE work at a national level and on the national NIMHE Management Board.

At the time of writing this report an 'expression of interest document' is being developed to identify an independent organisation or organisations to facilitate the development and delivery of the national networks.

Chapter 4 – The Future Implementing the Making a Real Difference Products

At a meeting between the CSIP service user and carer leads and the Directors of the Development Centres on the 27th September 2006, it was agreed that careful thought needed to be given to how the products presented by the Making a Real Difference Project would be fully implemented throughout each and every RDC within CSIP as well as any national work programmes which are ongoing.

It was agreed that responsibility for the implementation of the Making a Real Difference products needs to ultimately lie with the Directors, and the performance management of each Development Centre will lie with the NIMHE Management Board and the lead national NIMHE Director.

A handover plan has now gone to the NIMHE Board detailing this handover of responsibility from the Making a Real Difference steering group to the members of the Board. Within this report two recommendations were made.

4.1 Recommendations for implementation

1. It is expected that each RDC Director will ensure that an implementation plan, highlighting how their RDC will adopt the resulting policies, procedures, systems and guidelines will be produced.

The plan will need to set out;

- a. timescales for implementation of each product
 - b. identification of someone with personal responsibility for delivering the implementation plan,
 - c. the responsibility of the RDC director for ensuring the implementation plan remains a priority.
2. Each RDC should develop a benchmark of the current situation regarding involvement within their RDC. This will enable progress to be measured in future performance management procedures.

4.2 Post Project Review

Recommendation 20 of the Making a Real Difference report states that;

“NIMHE should review the impact of the steps taken as a result of this review in two years time.”

The responsibility for facilitating this review has been given to the Project Director and will be overseen by the NIMHE Management Board.

It is expected that the involvement of people with lived experience of mental illness, their friends and families who care for them, will be integral to this post project review.

Glossary

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

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

Other Terms used within this report include;

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