Care Services Improvement Partnership CSIP

National Institute for
Mental Health in England

Valuing Involvement

Strengthening Service User and Carer Involvement in NIMHE

Leadership Recommendations:

Strengthening the support available to people who become involved by making appropriate training available.

A product of the Making a Real Difference Project (see overview for details)

Overview

The Making a Real Difference Project was undertaken in direct response to the HASCAS review of service user and carer involvement in NIMHE. This resulted in the Making a Real Difference report.

The following leadership recommendations are designed to address some of the recommendations made within the report. They provide NIMHE and its staff with some key suggestions regarding how they can support the service users and carers involved in their work programmes, by providing them the opportunity to access the appropriate training to gain the skills they feel they need to effectively carry out their roles.

Who are the leadership recommendations for?

NIMHE Staff and Volunteers

- All NIMHE staff members should be aware of the need for people involved to regularly access training.
- All work programmes should have involvement built into their delivery. All people involved should have their training requirements assessed when they identify their support needs at the beginning of their involvement.
- Training requirements should be continually assessed to ensure that they haven't changed in line with the role a person is being asked to undertake.

People Sharing Their Expertise to Inform NIMHE's Work

- Everybody involved should be able to receive regular training and development.
- Anyone who is involved in the development and delivery of a NIMHE programme should ensure that they identify any training needs to the work programme lead.
- Training needs should be reassessed as and when an involvement role changes, that is, when a person goes from a regional involvement role to a national one.

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More than 340 service user and carer groups and individuals were invited to participate. We also invited 101 people in commissioning roles across PCTs, Local Authorities and Mental Health Trusts to participate in the research. We received responses from 29 service user and carer groups and 12 commissioners.

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Executive Summary

The following recommendations are the result of a consultation process to understand the training and development needs of people who are currently involved with various organisations in advisory roles, including NIMHE and all of its work programmes.

Five broad recommendations were made regarding making training available to ensure that the people have the competencies and skills appropriate to the involvement role they are undertaking.

Recommendations Regarding Leadership Training

1. Training is best delivered locally to reduce travel and increase local capacity building. People need to be able to access courses at the appropriate level for them with opportunities to move on to other levels.
2. Local and regional training programmes should be supported by national initiatives in terms of funding, co-ordination of effort and shared learning.
3. When planning and commissioning training accreditation should be sought from the outset, as accredited training leads to opportunities for social inclusion through education and employment.
4. The findings of this report show that CSIP and NIMHE have already acquired a great deal of expertise in commissioning and providing training. This effort needs to be co-ordinated, sustained and extended to other areas around the country to embed the benefits and learning.
5. Consideration should be given to how participants can apply their learning in whatever ways are appropriate to them.

Introduction

This document was written in conjunction with the Commissioning Guidelines for supporting local involvement, part of the Making a Real Difference Resource Pack.

The two documents were developed to address recommendations 5 & 11 of the Making a Real Difference report;

Recommendation 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.

Recommendation 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.

The overall aim of our task – commissioning and capacity building

We interpreted our task as being about improving the capacity of service users, carers and families to take part in local, regional or national involvement, service improvement work, self-help support and service provision.

The following leadership recommendations specifically focus on addressing the issues raised in recommendation 11. They are designed to assist NIMHE and its staff in developing training and support packages which will effectively support and build the capacity of people who are involved in NIMHE and its work programmes

Chapter 1 - Background

Since the 1980s there have been small training initiatives at local and national level, devised by service user organisations in partnership with the statutory and voluntary sector, to provide skills and support for service users. There are a range of publications and training packs in existence, some still in use. The authors of this report are not aware of any similar initiatives during the same period for carers and families.

A literature review (Wallcraft 2003b) of these service user courses and training packs was produced for the Sainsbury Centre for Mental Health (SCMH)'s national programme to develop training in service user empowerment and leadership. SCMH went on to pilot its training with NIMHE London and NIMHE South East, as we will document below.

Wallcraft (2003b) found that developers of training courses sought to meet the sometimes conflicting demands from service users and from mental health professionals;

- Service users needed to know how to look after themselves better, be more assertive, confident and skilled in presenting, and to seek proper payment and respectful treatment when doing involvement work.

- Professionals wanted training to result in a cohort of service users who were able to demonstrate authenticity, representativeness and professionalism in speaking about service user perspectives.

The courses addressed the following sets of skills which are relevant for the present study:

1) personal empowerment and self management
2) collective empowerment, advocacy and action
3) user involvement, consultancy and training

As will be seen in the following document, these sets of skills correspond to the 'core' and 'specific' skills levels of the Johnson model, which we have used as an analytic tool in this study. The first and second of the above list could be termed 'core skills' and the third 'specific skills'.

Chapter 2 - Method

The following document will only address the training and development needs element of Recommendation 11 of the Making a Real Difference report. Induction to involvement has been covered in the 'Induction Passport' found in the Making a Real Difference Resource Pack.

Our approach was to seek out examples of positive practice already available across the CSIP regions in terms of training and support for leadership at different levels of experience. We also looked beyond NIMHE for other similar examples of training courses and support systems for service user and carer leadership.
We examined the content and evaluation of these programmes along with a number of other programmes and training models and from these we have created a distillation of the common elements of good practice in training and empowerment at different levels of experience.

We have used an existing model for service user and carer leadership training which is described below.

2.1 Model of service user and carer leadership training

The Johnson model comes from a presentation produced as a result of extensive feedback gathered from service users and carers at a leadership workshop held in Leicester in November 2004 and Birmingham 2005. The development of the model was led by Paul Johnson from the North East, Yorkshire and Humber Regional Development Centre. The presentation illustrated the major themes for leadership training that were expressed by the participants to assist them in influencing service improvement.

2.2 Understanding and using the Johnson model

Figure 1 of the Johnson model identifies three levels for involvement, and three skills levels required to be involved at each particular level. It indicates a pathway for moving from one level of involvement to another, for example, from being involved in one's own personal care and contact through operational and service management to involvement at a strategic level. It shows some examples of these skills.

The skills can be used regardless of whether one is involved locally, regionally or nationally. For instance, assertiveness and handling meetings are skills which would be required whether in a CPA meeting or as a member of a Trust board, RDC stakeholder group or national task force.

Figure 1. Involvement and Partnership Working Pathway

Core Skills	Specific Skills	Specialist Skills
Assertiveness	Recruitment & Selection	Organisational Governance
Confidence Building	NSF & L.I.Ts	Health & Social Care Law
Presentation Skills	C.P.A level 2	Finance & Planning
Handling Meetings	Monitoring & Audit	Policy and Guidance
Stress Management	Research	Public Speaking
Communication Skills	Acute Care	Performance Management
I.T. Training	Primary Care	
P.A.L.S	W.R.A.P	
Advocacy	Training	
C.P.A Level 1		

Corporate & Strategic Governance

Operational & Service Management

Personal Contact & Care Pathways

- **Core Skills:** These are the underpinning foundation skills that enable individuals to feel comfortable in leading decision making in their own treatment and activities which impact on their everyday lives.

- **Specific Skills:** these build on the core skills and will give individuals the confidence and competence to lead challenges and improvements in the way services are delivered

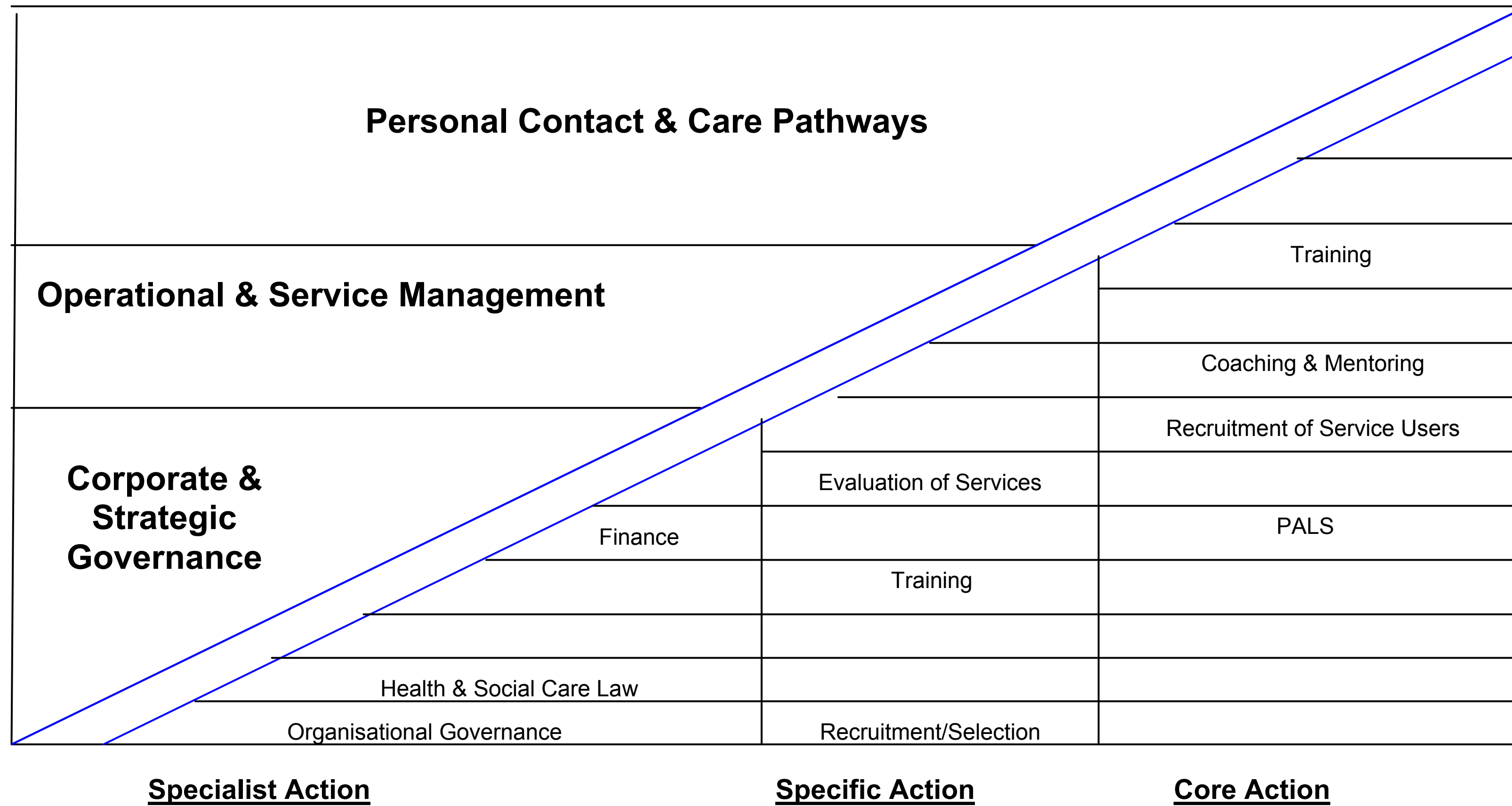
- **Specialist Skills:** these are advanced skills in leadership and service improvement that will enable individuals to influence and lead change and improvement at a strategic level.

These module examples don't represent an exhaustive list – rather they should reflect local need. The structure has entry points at different levels dependent upon individual need.

In Figure 2 we can see how skills acquired by following the 'Involvement Pathway' translate into actions. Again, the model illustrates just a few examples of many possible actions. Core, specific and specialist areas of action form what Johnson describes as 'The Pillars of Involvement'. All three pillars are essential aspects of active service user involvement in personal care, service delivery and improvement, management and governance. The core, specific and specialist skills set out in Figure 1 are requisites to prepare service users for these actions.

We have used the Johnson model to help understand and categorise the various models of training and support which we have identified across the NIMHE/CSIP regions.

Figure 2 Pillars of Involvement.



Chapter 3 - Findings

We looked at courses for service users and carers being run in the South East, the North West, the North East and London, as well as one national leadership course. All appear to be fairly successful though still at a relatively early stage of development. The evaluation results of these courses indicate that they do make a real difference for those service users and carers who take part in them in terms of the confidence, knowledge and skills needed for involvement in service improvement work. We have used the Johnson model as an analytic tool to categorise the levels of skills provided by the courses.

3.1 Courses providing mainly core skills

We found that only two courses focussed primarily on core skills.

One was a four-day course for carers run by London Development Centre (LDC) (see Appendix 6) and the other was a course for service users funded and managed by the South East Development Centre (SEDC) in 2004 and repeated in 2006.

The course for carers was run in February 2004 and was for carers on various LDC steering groups and networks. It was run by LDC's Carers Advisory Group (LDC-CAG) and First Resource (a social firm who delivered the training).

The course content included:

- What is mental illness?
- The care-giving cycle
- Working in groups and meetings
- The stress vulnerability model
- Life stages and coming to terms
- Treatments
- Disclosure
- Stereotypes
- Presentation skills and assertiveness
- Communication and problem solving
- Beliefs and behaviour
- Coping with emotions and anger management

The purpose of this course was to provide personal support and coping skills for carers who worked with LDC, and could be seen as an entry-level core skills course that would provide a basis for future specific training.

The SEDC course was developed and led by the Sainsbury Centre for Mental Health (SCMH) as part of its empowerment and leadership training

programme for service users. The 2004 course was one of the first pilots for the SCMH programme. SCMH carried out an evaluation of the courses so that the planning of the 2006 course took into account the evaluation findings about the 2004 course. The SCMH training model was envisaged as a basic empowerment course to provide entry-level core skills and some specific skills for service users at an early stage of their personal development and involvement work.

Consultation on content and methods of delivery were built into the model. As envisaged by SCMH prospective trainees in the SEDC area were invited to help plan the training in terms of content and delivery methods. This was done through ‘Taster Days’, when the content of the available training modules could be discussed and tried out. Service users were invited to say which core skills were most important for them and to ask for any specific additional skills (from a range available) which they would like added to the course, for example, use of IT.

The content of the SCMH courses for SEDC included the following:

- Networking
- Knowledge and learning of new skills
- Putting skills in practice
- Gaining confidence
- Assertiveness
- Sense of purpose and direction
- Understanding organisations
- Recovery
- Conflict and negotiation in groups
- Positive risk-taking
- Strengths approach
- Working in formal groups
- Chairing meetings
- Leadership skills
- Drama workshop (for presentation and public speaking)

The majority of these topics were pitched at the level of personal development for those with not much prior involvement experience but could also be used to build on some prior experience of taking part in SEDC meetings, Local Implementation Team involvement, service user forums and similar involvement work. People who already had a great deal of skills and experience in involvement work would most likely have found these courses too basic, and indeed this was a complaint by a few of those attending.

3.2 Courses providing mainly specific skills

Three sets of courses we looked at were more focussed on specific skills, though most of them also offered some core skills. They were aimed at service users and carers who were already doing involvement work and wanted to enhance their knowledge, skills and confidence to take on greater challenges.

London Development Centre (LDC), like SEDC, worked with SCMH to run a pilot course in 2004, but the second course, in 2006, was funded by SCIE, and SCMH were not involved. Both courses were evaluated, the first one by SCMH. The courses offered a balance between core and specific skills, with the second one in 2006 moving more towards specific skills following feedback from the 2004 participants, some of whom found the course not sufficiently challenging.

The content of the LDC courses was:

- strengths assessment
- positive risk taking
- working with groups
- formal meetings
- identifying critical information
- trainer training
- conflict resolution
- working with change
- policy and structure information.

NIMHE North West Development Centre (NWDC) collaborated with Liverpool John Moores University and the Five Boroughs Partnership NHS Trust Learning Foundation to provide a leadership and empowerment module to service users and carers. The course started in 2005. The content of the course includes:

- Leadership and empowerment
- Models of mental health and issues of oppression
- History of mental health services
- History of the service user movement
- Mental health organisations
- Service user perspectives
- Law and social policy
- Models of advocacy
- Meeting skills
- Problem based learning
- Positive communication
- Leadership skills

This course is clearly focussed on specific skills though some core skills such as meeting skills are included and there are study skills courses available.

3.3 Courses providing mainly specialist skills

We identified one course offering mainly specialist skills. This is a national course, 'Learning Through Professional Practice (Service Users and Carers as Mental Health Service Improvement Leaders)'.

This is a one-year course run jointly by the University of Surrey and NIMHE and is based in the University of Surrey's European Institute of Health and Medical Sciences. It is part of the Undergraduate Framework for Lifelong Learning in Health and Social Care practice.

The course covers:

- Process redesign including process mapping
- the '10 High Impact Changes'
- Human dimensions of change
- Engaging stakeholders
- Managing demand and capacity
- Values based practice
- Appreciative inquiry
- Creativity and innovation engaging stakeholders
- Introduction to leadership – policy into practice
- Lean thinking
- Plain english and report writing
- Leadership
- Developing your own style as 'Improvement Leaders'
    - Training as trainers
    - Competencies for improvement
    - Evaluation
- Presentation skills
- Project management
- Statistical process control
- Monitoring and evaluation

3.4 Common and differing features of the courses

Involvement of service users and carers

The courses involve service users and carers as part of the course steering groups. The LDC-CAG, LDC and SEDC courses negotiated the content of the course with the steering group and with potential participants. The national course was developed based on consultation with service users and carers and of the three course managers, one has a carer background and one a service user background. The LDC and SEDC courses included a high proportion of service user trainers. Evaluation and feedback is another important way of involving service users and carers. Most of the courses have been evaluated through the use of feedback sheets, and in the case of the SCMH pilot courses also some qualitative interviews.

3.5 Aims of the courses:

London Development Centre – Carers Advisory Group (LDC-CAG)
- to support carers who work with London Development Centre

South East Development Centre (SEDC)
- The enhancement of personal empowerment, skills, confidence and assertiveness
- Greater sense of purpose and direction
- The development of leadership skills and local networking

London Development Centre (LDC)
- For participants to develop their skills in order for them to be more effective in their existing roles in service-user involvement and be better placed to take up new opportunities
- To test, evaluate and improve the model of leadership development for service users
- For participants to be better equipped to train and support other service users to do involvement work
- To create a cohort of service users with skills to help with future LDC work including running leadership courses

North West Development Centre (NWDC)
- To enable people who have used mental health services to develop the skills and knowledge to make a meaningful contribution to service decision making and planning.
- The course will embrace the challenges of diversity and the invaluable contribution this makes to understanding mental health issues.
- It is hoped the students' insights will help improve services.

National
- to support flexible learning opportunities for mental health service users and carers to develop a set of service improvement skills including change management skills
- to train up a cohort of service users and carers as service improvement leaders on a course that is academically accredited and meets the requirements of the NHS Knowledge and Skills Framework (KSF).

Numbers of places

The LDC-CAG course was for 8 carers. The LDC, SEDC and National courses had places for 18-20 people while the NWDC course has 45 places.

Who were the courses for?

The LDC-CAG course was for carers only, LDC and SEDC and NWDC courses were for service users only. The national course was for service users and carers.

Support for participants

The course developers took into account the support needs of participants in differing ways. Most courses encouraged peer support and buddying. LDC-CAG and the LDC and SEDC courses offered staff support. On the SCMH pilot courses (LDC and SEDC) tutorial support was provided by the course leader. The NWDC course had the benefits of the university system, including a study skills course and university counselling and welfare services. Students were encouraged to identify a learning mentor and to develop a team approach to learning. The national course offered tutorial support from the course managers and students could also receive ongoing support through the NIMHE RDC Service Improvement Leads to apply their learning during the course. Academic support was provided by the university.

Length of course

The LDC-CAG course was 4 days over 2 weeks. LDC, SEDC and NWDC courses were from 8 to 12 days spread over 3-4 months. The SEDC course had half of its days in 2-day residential blocks. The national course was a one-year course with 12 taught days, 6 action learning set days and 6 masterclasses.

Training methods

All the courses use a mix of methods, including facilitated workshops, group work, problem-based learning, role play, sharing of experiences and knowledge. The national course had 12 taught days, 6 action learning set days and 6 masterclasses.

Accreditation

The LDC and SEDC service user courses and the LDC-CAG course were not accredited. SCMH, who developed LDC and SEDC courses looked into accreditation but found it would be too time-consuming and complex for the timescale of the project. Participants were only assessed on attendance with those who attended most of the sessions receiving a certificate of attendance.

However, the NWDC and National courses were both accredited and linked to universities. NWDC provides a University Certificate in Professional Development 12 CPD points at level 1, while the National course is taken from the Service Improvement module of the University of Surrey’s BSc in Clinical Practice and is accredited accordingly attracting 20 CPD points at level 3.

3.6 Positive outcomes of the courses

LDC-CAG trainees found the course useful and wanted it repeated, though some found it intensive and demanding.

LDC's evaluation showed that, for the most part, trainees gained significant support from each other and valued the opportunities to come together as a group. Lots of useful information was gathered which was used to improve the programme in terms of content, delivery and organisation. Another outcome was that one of the course participants was invited to Norway to speak about the course.

SEDC's evaluation showed that it had helped people identify personal strengths and skills, and build new relationships with others from across the area. Role playing was seen as a valuable learning tool. A South East User Forum was developed from the courses and this was seen as useful. The in-depth interviews showed some evidence of increased personal empowerment and recovery and some people took on new roles locally.

NWDC's evaluation said that students felt they had been given a good grounding in many aspects of mental health including social and medical models, historical perspectives, law and policy. A number highlighted chairing meetings as an example of something they had learnt from this course and put into practice. Respondents also stated that they now felt more able to effectively contribute to meetings they attended.
All of the respondents highlighted interpersonal skills as the main leadership quality they had developed as a result of the course. Some said that their ability to be assertive had developed and that they now felt more comfortable expressing themselves in interactions. Some felt that the course had contributed to their empowerment as a mental health service user consultant by enabling them to feel more confident when challenging others and expressing their own views. Some had gone on to use their skills in presenting, chairing or taking part in meetings, others were still reading and reflecting on their experience but hoped to be able to make more use of it later.

For the national course, internal evaluation by course participants is currently being planned. The use of 'talking heads' video stories is one method being considered.

External evaluation will be carried out following the conclusion of the pilot but no specific details were available at the time of writing this report.

3.7 What service users and carers value – in their own words

Here are some quotes taken from evaluations and individual interviews with course members on the courses:

SEDC

'At the start of a meeting I know what is my role and my expectations. If I am asked to contribute, I try to meet my commitments and prepare, I take a more disciplined approach. People generally want to be treated with respect, as human beings, whatever their role, so I treat them with respect, and acknowledge their pressures, but I still speak out.'

LDC

'Back in February, I was angry inside; I was stubborn and blinkered; my manner was rough. Nowadays, my anger is determination; stubborn has become purpose and my outlook is 360°. I feel assertive, capable and confident.'

'The most valuable thing about the course was working with others – there was good teamwork and it was good for our souls. If I have a criticism it's that techniques taught on the course weren't always backed up by handouts to help you apply them in your own situation.'

'It's that FEAR that's stops me from getting on and getting ahead but something clicked at that first meeting. It was not the cakes and biscuits nor the endless cups of tea and coffee. I now believe it to be the enthusiasm of the organisers who treated me as an equal. I was spoken to and not spoken at. I was asked questions and my answers were written down. Nothing seemed to be too much trouble and that was a first!'

'The course helped you gain an understanding of mental health organisations at all sorts of levels…and you could see how your contribution fitted in.'

'The course far exceeded what I expected. It has motivated me to think about doing an academic course.'

NWDC

'I will now be able to speak more knowledgeably and authoritatively which gave them more confidence to speak at meetings, and to support other service users to speak'.

'I'm amazed how much I have learned while having such great fun. I wish to thank the team on the delivery of such an eye opening informative course. I have gained so much. I owe them a great debt of gratitude and can't thank them enough'.

National

'I have gained a little knowledge of a wide range of subjects, I didn't know about before.'

'The people on the course are great. They are from a diverse range of life, work and cultural backgrounds. We work well as a group, have bonded quickly and well.'

'Action learning sets are good. I had never experienced these before. They have been amazing, the best part of the course. We learn from each other. There is some learning from each other on the taught days, but most of our shared learning is in these sets.' 'We learn from hearing about each other's projects. We try to look at solutions and provide peer support. We all receive tremendous support from one another. This is the part which has gone best for me.'

3.8 Outcomes in terms of establishing 'Pillars of Involvement' (Johnson Model Fig.2)

The Johnson Model (Fig 2) reverses the order of Fig 1 putting personal contact and care pathways at top level of importance above operational and strategic management. The three levels of skill – core, specific and specialist – are now translated into core, specific and specialist actions, which form the 'Pillars of Involvement'. The evidence from the evaluations of the training courses does seem to indicate that providing training to service users and carers in core, specific and specialist skills prepares people for these levels of action.

Core skills and actions

Core skills may include assertiveness, confidence building, presentation skills, handling meetings and communication. People with these skills are likely to be able to take better care of their own mental health, speak out for themselves and others, and take part in delivering training. The results of the evaluations showed that people felt better able to manage their feelings, take a greater part in meetings, and consider further training. The core skills are also a basis for specific and specialist action.

Specific skills and actions

Specific skills enable people to take part in operational and service management, for example, meeting skills, knowledge about mental health services and policy, and basic research skills. For instance, some people now felt confident about chairing meetings.

Specialist skills and actions

Specialist skills are related to organisational development and governance. Examples may include understanding practical applications of government policy, health and social care law and finance. Knowledge of this type can enable service users and carers to take part in strategic planning and as members of governing bodies, for example, non-executive directorship of Trust Boards. The applied skills and conceptual tools being taught on the National course are likely to help with this level of work.

Chapter 4 - Conclusions

1. This report shows that training programmes for service users and carers are highly valued and appreciated by them, especially if course managers are responsive to the needs of trainees, involving them in the planning and taking on board the results of evaluations.
2. Training can help individuals with their own recovery, empowerment, self-management, and employment.
3. Training enhances local capacity within service user and carer groups and the voluntary sector by raising people's levels of skill and confidence and also by encouraging networking.
4. Delivery of core and specific training modules is usually offered at a local or regional level.
5. We found that although accreditation was recognised as desirable and valuable for participants the reality of achieving it could be difficult and time-consuming.
6. Generally, the support offered to participants was highly valued. Forms of support include: peer support, support from course staff and Development Centre staff, study skills classes, tutorial and mentoring support.

Recommendations

1. Training is best delivered locally to reduce travel and increase local capacity building. People need to be able to access courses at the appropriate level for them with opportunities to move on to other levels.
2. Local and regional training programmes should be supported by national initiatives in terms of funding, co-ordination of effort and shared learning.
3. When planning and commissioning training accreditation should be sought from the outset as accredited training leads to opportunities for social inclusion through education and employment.
4. The findings of this report show that CSIP and NIMHE have already acquired a great deal of expertise in commissioning and providing training. This effort needs to be co-ordinated, sustained and extended to other areas around the country to embed the benefits and learning.
5. Consideration should be given to how participants can apply their learning in whatever ways are appropriate to them.

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Viv Lindow's Rowntree Report on Commissioning Self Help
Course documents
Carers Help Carers http://www.bath.ac.uk/carershelpcarers/
Groundswell http://www.groundswell.org.uk/index.php
YoungMinds (2006). A Call to Action: Commissioning Mental Health Services For 16–25 year-olds.
http://www.youngminds.org.uk/sos/SOS_YM_Commissioning.pdf

Hear Our Voice (for young people with mental distress in Cornwall)
http://www.eefo.net/index.cfm?section=home

Off the Streets and Into Work - http://www.osw.org.uk/
OSW is a registered charity that tackles homelessness by supporting individuals to access education, training, volunteering and employment.

ODPM (2004) Mental Health and Social Exclusion
http://www.socialexclusion.gov.uk/downloaddoc.asp?id=134

The National Social Inclusion Programme (NSIP) at NIMHE has brought together the work of government departments and other organisations in a concerted effort to challenge attitudes, to enable people to fulfil their aspirations and to significantly improve opportunities and outcomes for people with mental health problems.

Awards for All - http://www.awardsforall.org.uk/
Awards for All is a Lottery grants scheme for local communities.

Esmée Fairbairn Foundation is one of the largest independent grantmaking foundations in the UK, making grants to organisations which aim to improve the quality of life for people and communities in the UK, both now and in the future.
http://www.esmeefairbairn.org.uk/about_us.html

Futurebuilders (*Future*builders is a £125m fund that plans to deliver an increase in the scale and scope of the public services delivered by the voluntary and community sector (VCS). www.hm-**treasury**.gov.uk/media/D31/43/**futurebuilders**(309kb).pdf

Comic Relief supports long-term projects, helping people to help themselves. http://www.comicrelief.com/

Tudor Trust is an independent grant-making trust which supports organisations working across the UK. They aim to support work which addresses the social, emotional and financial needs of people at the margins of society. http://www.tudortrust.org.uk/

Bridge House Trust makes grants in excess of £17 million a year to charitable projects benefiting the inhabitants of Greater London http://www.bridgehousegrants.org.uk/BridgeHouseTrust/

Capital Volunteering a pan London programme which aims to tackle issues of mental health and social inclusion through volunteering. http://www.capitalvolunteering.org.uk/

The King's Fund is an independent charitable foundation working for better health, especially in London. They carry out research, policy analysis and development activities, working on their own, in partnerships, and through funding.
http://www.kingsfund.org.uk/

Camphill Communities build intentional communities with people of all ages who live with disabilities. http://www.camphill.org.uk/

UnLtd supports social entrepreneurs - people with vision, drive, commitment and passion who want to change the world for the better, by providing a complete package of funding and support to help individuals make their ideas a reality. http://www.unltd.org.uk/

Full Cost Recovery
http://www.fullcostrecovery.org.uk/main/index.php?content=home

Glossary of terms used

NIMHE	National Institute of Mental Health Partnership programme
CSIP	Care Services Improvement Partnership
Diversity	The term ‘diversity’ can be understood as referring to the diversity of people’s experience, support needs and mental health issues, as well as ethnicity, culture, spiritual beliefs, gender, sexual orientation, social class, age and disability.
LDC	London Development Centre
MARD	Making a Real Difference Project
RDC	Regional Development Centre
Social exclusion/inclusion	‘Social inclusion is about helping to ensure that everyone feels able to contribute and be involved in his or her local community. This is aimed especially at people who often have to overcome additional barriers to enable them to become involved in their community, such as gypsy and travellers and young people. Or to put it another way, it is about tackling ‘social exclusion’. The Social Exclusion Unit, a government department defines social exclusion as: “ the shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low income poor housing, high crime environments, bad health and family breakdown”.’ (http://www.devonrcc.org.uk/page/social_inclusion_programme.php)
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.

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

Appendices

Appendix 1 - Working Group List

Mark Leveson – Project Lead and Working Group Chair
Ali Davies – Programme Director and Project Sponsor
Gemma Hughes – Programme Director
Emma Raver – Project Support Manager
Dorin Varza – Project Support Manager
Margo Fallon – Service Improvement Lead
Clive Stevenson – Service Improvement Lead
Lesley Carter – Service Improvement Lead
Jan Wallcraft – Consultant
Christine Lewis – LDC Carers Associate
Fiona Hill – LDC Service User Associate

Appendix 2 – carer involvement table

TABLE TO ANALYSE CARER INVOLVEMENT IN MENTAL HEALTH, AND SUPPORT NEEDS.

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
Involvement at personal and individual level					
• Providing day-to-day care • Financial and practical help to the service user. • Meetings with health and social care professionals • Experience of compulsory	Better understanding of mental illness, and mental health services Better outcome, recovery for the Service users Good quality of life and	• Support in managing their caring role • Good access to NHS Services, such as in-patient, community mental health, and primary health care services • Culturally sensitive services	**Commissioners** (PCTS & LA s) Commissioning services for carers eg support workers, grants to local organisations (including BME) and carers' training.	• Develop, promote and spread good practice. Ensure that carer issues are integral to work streams and networks. • Monitor availability and effectiveness of services to individuals eg carers' support workers, carers' assessments	• Advise about what carers want • Commission, or lead work for carers (eg carers charter booklets) • Develop carer-led work through the carers' network.

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
treatment under mental health act. • Contact with criminal justice system. • Coping with their own needs as carers • Member of support group	good health for the carer	• Day services and supported housing for the service user • Information about mental illness, good communications • Practical info including benefits, housing advice • Training in caring role • Peer-group support Conferences, networks	**Statutory Providers** Ensure organisation is carer-friendly: eg staff training, awareness-raising, protocols on wards	• Ensure equality issues are addressed	• Monitor work on support to carers (eg Support workers, assessments) • Ensure Carers interests are integral to workstreams and network • Monitor work for and with carers

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
		Support for meeting carers' own needs • Carers support workers • Practical info. and advice • Carers' assessment and effective follow-up • Support groups • Respite/breaks • Leisure and employment • GP carers' register	**Voluntary Sector** Pressure groups (eg Rethink) often best source of advice, info Help-lines, training. Local Vol orgs. Should include carers in their work. Carers on management boards.		

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
Involvement at local level					
• Member of local support group • Local BME user and carer groups • Carer rep on LIT and other user-carer forums • Interview panels, or staff training for Trust or LA. • PPI Forum member • Non-exec board member of PCT or MH Trust	• Improved services across a range of MH services including primary care. • Better SU&C involvement in services and decision making • Better local awareness of MH issues	• Understanding of systems and structures • Knowledge of MH issues outside their own experience • Training where needed for representative role and other skills eg interviewing. • Mentoring and buddying • Good admin support from organisations (eg notice of meetings,	As in section 1 Provide induction, training and support to carers. Involve carers in relevant staff training events Be flexible in meeting and communicating with groups. RDCs, vol orgs (eg Rethink) websites, Conferences, networks etc are the best source of general information. MH Pressure groups support local campaigning	• As in sectn 1 • Support carer – involvement through training, providing information and opportunities for networking. • Identify and develop good models for user/carer involvement and user/carer led services • Work with commissioners and providers to encourage them to invest in and support carer involvement.	As in section 1 Develop carers website Carers' network and conferences are an important way of supporting local involvement. Monitor progress and performance [Consider producing a "handbook" for carers involved

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
• Trustee or on management committee of voluntary organisations • Responding to surveys, focus groups, local consultations • Volunteering, befriending • Mental health promotion • Campaigning Lobbying • Media work • Fundraising	• Less stigma • Improved mental health promotion.	background papers etc). • Timely access to good information • Payment of expenses and fees • Networking and contact with local user and carer groups • Lectures, conferences seminars • Support from campaigning and lobbying organisations • May need media		• Monitor SU&C involvement in MHTs and LAs	at this level – as a continuation of the Carers Charter work]

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
		training			
Involvement at Regional level					
Rethink Regional Reference groups and networks network and regional events general regional and sub regional planning which may include health issues BME networks Campaigning, Lobbying Media work Anti stigma work	To identify and address regional issues To raise the profile of MH across the region Networking, and information sharing	• Good knowledge of mental health issues, strategies and priorities at regional level • Knowledge and understanding of how systems, structures and organisations work. • Induction, Buddying or mentoring • Attendance at regional and national	Largely outside the remit of local statutory commissioners or providers – unless the carer is representative of a local body at regional or national level. CSIP development centres provide regional focus National bodies, eg RCP, Mental Health Foundation provide information. Government websites (eg uk online) MH pressure groups support campaigning and provide media training.	Networking events and conferences. Carers may need free places or travelling expenses. Website and monthly bulletin Website links to key government initiatives and documents.	Ensure that carers' needs are included in RDC events etc Support involvement at all levels through the carers network. Develop carers database – and an on-line network for carers.

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
		conferences • Media training • Financial support for attendance at conferences • Carers who become involved at regional and national levels probably already have a good knowledge-base. • They probably have skills and experience gained from other areas of their life(eg paid or voluntary work)	SHIFT supports anti stigma work Provide free places and travel at Regional and national conferences.		Ensure that carers are aware of, and have access to the main sources of information. Develop carers section on website ensuring this has links to major mental health organisations and policies.

Area of involvement. and ways carers are "involved"	What are the objectives?	What are carers support needs to make their involvement effective?	How can statutory and voluntary organisations support carers?	How can RDCs strengthen support to carers?	How can carer networks influence this work?
Involvement at National Level					
Trustee/ board of national organisations Participant in national consultative bodies Lobbying and campaigning	To ensure that strategy and governance includes carer interests To ensure that carer interests are included. To provide local "grassroots" input at national policy level	See section on regional involvement above	See section on regional involvement above	See section on regional involvement above	See section on regional involvement above