Valuing Involvement

Strengthening Service User and Carer Involvement in NIMHE

Resource Pack for Trainers and Facilitators

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 resource pack is designed to address some of the recommendations made within the report by providing a comprehensive training resource pack for the development of NIMHE and its staff’s understanding and capacity to effectively involve people in all work programmes.

Who is the training pack for?

NIMHE Staff and Volunteers

- All NIMHE staff members should be able to regularly access training on involvement. This should be a mandatory requirement of NIMHE staff and volunteers.
- All NIMHE staff should receive regular update on involvement.
- Staff and volunteers should ensure that they identify any training needs within their supervision.
- Line managers need to make provision for training to be made available when a need is identified.

People sharing their expertise to inform NIMHE’s work

- Any involvement training should be made available to anyone with experience of mental health problems, their friends and families whenever the need is identified.
- This training should, whenever possible, be delivered by people with experience of living with mental illness, or for caring for a person with those experiences.

NIMHE Boards, Commissioners and Performance Managers (including external stakeholders)

- All NIMHE work programmes should provide regular feedback which reflects the values within the training pack.
- When monitoring and evaluation of work programmes identifies a training need regarding involvement, this must be brought to the attention of the appropriate person.
- This training should be made available to all stakeholders working with or on behalf of NIMHE.
Acknowledgements

The Policy for Involving Service Users and Carers was developed and written by Diane Bardsley on behalf of the Making a Real Difference Project.

This document was produced by the South West ‘Making A Real Difference Working Group’ which included Service Users and Carers.

Diane Bardsley (Project Lead)  Gwen Butcher
Lucy Pearce                  Eddie Godfrey
Emma Laughton               Mark Norman
Louise Neville              David Pennington
David Dixon                  Julie Armstrong
Sally Luxton

The make up of the steering group was as follows;

<table>
<thead>
<tr>
<th>Designation</th>
<th>% of group</th>
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<tbody>
<tr>
<td>CSIP Staff</td>
<td>30%</td>
</tr>
<tr>
<td>People with experience of using mental health services</td>
<td>40%</td>
</tr>
<tr>
<td>People with experience of caring</td>
<td>30%</td>
</tr>
</tbody>
</table>

We wish to thank for their support and advice:

Paddy Cooney                   John Wood
Kate Schneider                 Karen Stuckey
Steve Onyett                   Liam Gilfellow
David Goodban                 Sally Prescott
Linda Parker                   Pam Taylor
Ross Hughes

The South West Making a Real Difference consultation event was attended by approximately 110 people.

This document was informed by the expertise of people from the following groups and organisations;

Advocacy in Somerset  Carers and Relatives Mutual Support (CARMS)
Anchor Project        Carers Support North Wiltshire
Avon & Wiltshire Mental Health Partnership NHS Trust  Care Services Improvement Partnership (CSIP) North East, Yorkshire and Humber Regional Development Centre
Bath and North East Somerset Council  CSIP South West Making a Real Difference Workgroup
Bath and North East Somerset Primary
Care Trust (PCT)
Battle Against Tranquillisers (BAT)
Bristol PCT
Bwerani Multicultural and Inclusive Resource Library  CSIP South West Black and Minority Ethnic (BME) Network
We would also like to say thank you to the service users and carers who did not necessarily belong to any of the above groups but who also contributed to this document.
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Foreword

Increasingly mental health service users and carers are being involved within health and social care organisations. Whilst the importance of involvement is recognised sometimes there is a difficulty in translating the commitment into practice.

This training resource has been developed following a report by HASCAS (Making A Real Difference) 2004, which looked at involvement within the National Institute for Mental Health England (NIMHE) which is incorporated with the Care Services Improvement Partnership (CSIP). Following this report a series of recommendations were made to improve involvement of service users and carers within the work of NIMHE and CSIP.

Although the report looked at developing resources for NIMHE this training resource is applicable to people wishing to engage mental health service users and carers within their work, across a range of health and social care settings.
Chapter 1 - Guide to the Training Resource

1.1 About the Training Resource

This Training Resource pack aims to stimulate thinking and to provide ideas about how to actively and meaningfully involve service users and carers within current health and social care services, service development and policy making.

This training should help develop:

1. Greater understanding and appreciation about the value of involving service users and carers.

2. Knowledge and skills on models and methods of involving service users and carers within their work and organisations.

3. Organisation change through involving service users and carers.

This resource material looks at both service user and carer involvement. Although there are differences between these two groups there are also important similarities where they share an agenda of wanting a mental health service that is modern, up to date, well resourced with workers who listen and are responsive. Both groups are involved in order to influence the development and improvement of the mental health system.

This training resource has two sections:

1. A guide that gives an overview of the Training Resource with guidance for trainers and facilitators.

2. A range of exercises that include materials for trainers and handouts for participants.

Although these materials were developed with mental health service users and carers they have not been formally evaluated or accredited.
1.2 How to use the training pack

The exercises in this pack are presented as tools that can be used when putting together a training session on ‘Effectively Involving Service Users and Carers’. They are suggested exercises and can be adapted to suit your own facilitation styles.

The contents matrix at the beginning of this resource pack offers facilitators the opportunity to view at a glance the specific categories of each exercise. Each exercise has clear learning outcomes and easy to follow delivery instructions.

The Categories used are:

- Getting to Know Each Other – Energisers, Warm-ups and Finishers
- How to Involve Service users and Carers
- Setting The Context of Involvement
- Developing Action

A useful way of developing session plans from the exercises listed within the contents matrix exercises would be to incorporate elements from each of the four categories.
### 1.3 Contents Matrix

<table>
<thead>
<tr>
<th>Section</th>
<th>Page no</th>
<th>Getting to Know Each Other</th>
<th>How to Involve Service Users and Carers</th>
<th>Setting The Context of Involvement</th>
<th>Developing Action</th>
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</thead>
<tbody>
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<td>97</td>
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</table>
1.4 How to deliver or facilitate the training

This training resource was informed by the principles of adult education recognising that people learn in different ways and have different levels of experience and knowledge in service user and carer involvement which will inform and enhance the training. Therefore a range of different methods and interactions are incorporated within the exercises.

In the planning, development, delivery and evaluation of these training sessions service users and carers should be involved and appropriately supported.

Principles Of Adult Education

1. The teaching/learning process is interactive, cooperative and dynamic. There is a two-way interaction between learner and educator (“learners” and “educators”) with both the learner and the educator accepting responsibility for learning.

2. People are more important than anything else. The relationships between people are more important than the subject being taught or the learning technique being used.

3. The responsibility for teaching and learning is shared between the teacher and learner/teachers and learners.

4. The processes used are dependent on their applicability to the learner’s goals.

5. Learning involves not just information sharing but also values, attitudes, and skills.

6. The learning experiences are based on the needs of the participants and make use of their different backgrounds — that is, the activities are pitched or are designed to be pitched according to the experiences of participants;

7. Both learners and educators must be willing to progress from a supportive place to a place that encourages challenges. Adult learning is about identifying what ‘is’, validating it and then pushing on towards new beliefs, new values and new ways of knowing. Sometimes this might be confronting so the educational environment needs to be safe.

8. Evaluation should take place with learners and teachers talking about and writing about what seems to work and what needs to be changed.

9. Evaluation should take place with learners and teachers talking about and writing about what seems to work and what needs to be changed.

10. Learning takes place when learners interact positively with each other. Trust, security and mutual confidence assists learning.

11. Learning happens when there is an opportunity for participants to use practical concrete examples to test new theories and understandings. In a health framework this might take the form of a case study or a consumer story.

1.5 Training Evaluation

Pre and Post Training – Awareness Questionnaire

The following pre and post awareness questionnaire will help the facilitator to evaluate the effectiveness of the session.

The idea being to ask the participants to complete the questionnaire before the training session has begun so as to gain an appreciation of the participants understanding of the subject and personal value base before the training session has been delivered.

The questionnaire should then be repeated by the participants at the end of the session. This will allow the trainer/facilitator to assess the level of learning and affect of the training on the participants personal value base. This will allow the effectiveness of the training to be accurately evaluated.

Post Training - Session Evaluation

The Session Evaluation questionnaire should be completed by every participant at the end of each session. This will allow the facilitator and/or the training organiser to gain invaluable information into the effectiveness of the training session, the quality of the training materials and the relevance of the training to their participants.

Why is Evaluation so important?

Monitoring and evaluation not only measures how well the training has gone, but also helps the trainer/facilitator to be more effective in the delivery of the training in the future.

Monitoring and evaluating the training will help to assess how well it has gone in order to help it improve. It is about asking what has happened and why - what is and what is not working. It is about using evaluation to learn more about the effectiveness of the training, the trainer and the training materials, and then using what has been learnt, to improve the training session.
Pre and Post Awareness Questionnaire

Please rate the following in order for us to be successful in this process. We need you to be honest as all information is treated in the strictest confidence.

0 is the lowest score and 10 the highest.

Please circle the number you feel most appropriate:

1. The importance of service user and carer participation in the work of your organisation
   0 1 2 3 4 5 6 7 8 9 10

2. The importance of service user and carer participation in your work
   0 1 2 3 4 5 6 7 8 9 10

3. I have little or no difficulty in contacting a diverse representation of service users and carers
   0 1 2 3 4 5 6 7 8 9 10

4. I always have full and representative service user and carer participation in my work
   0 1 2 3 4 5 6 7 8 9 10

5. Please rate your knowledge of the CSIP Service User and Carer Participation Guidelines
   0 1 2 3 4 5 6 7 8 9 10

6. When attending meetings I ensure there is service user and carer participation
   0 1 2 3 4 5 6 7 8 9 10

7. My knowledge of the remuneration policy for service user and carer participation at meetings and events
   0 1 2 3 4 5 6 7 8 9 10

8. The involvement of service users and carers in my work is at what level

-------------------------------------------------------------------------------------------------
Token    Partial Involvement        Full Partnership
-------------------------------------------------------------------------------------------------
Session evaluation

Please rate the session you have just had, 0 being poor, 10 being superb

Name of session

The enjoyment of the session

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The session’s ability to get the message across

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The appropriateness of the session to the context of the training

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The appropriateness of the session to my work

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The mix of interactive and lecture style input into the session

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The appropriateness of the session to remain in the training workbook

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</table>
The information presented was clear and concise
0 1 2 3 4 5 6 7 8 9 10
comments

The style of the presentation
0 1 2 3 4 5 6 7 8 9 10
comments

The length of the session was appropriate
0 1 2 3 4 5 6 7 8 9 10
comments

Quality of handouts
0 1 2 3 4 5 6 7 8 9 10
comments

Size of the group
0 1 2 3 4 5 6 7 8 9 10
comments

Opportunities for discussion with group members and facilitator
0 1 2 3 4 5 6 7 8 9 10
comments

Comments to assist further development of the session

The facilitator
Poor Superb
1 2 3 4 5 6 7 8 9 10
1.6 Example of a Session Plan

Topic: Understanding issues around service user and carer involvement

Participants:

Time Available: 6 hours

Objectives:
- To create a positive atmosphere
- To learn about the history of involvement
- To explore different motivations and variables which may encourage people to participate
- To consider the appropriate use of different methods
- Analyse some beneficial outcomes from involvement

<table>
<thead>
<tr>
<th>Time</th>
<th>Exercise name</th>
<th>Brief outline of activity (See individual exercises for details)</th>
<th>Resources</th>
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</thead>
<tbody>
<tr>
<td>10.00</td>
<td>Welcome, introductions &amp; housekeeping</td>
<td></td>
<td>Pre-awareness questionnaire</td>
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<tr>
<td></td>
<td>Pre-awareness question</td>
<td></td>
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<tr>
<td>10.15</td>
<td>Recognising the positives</td>
<td>Ask participants to talk to someone they know least well (not mentioning work). After 5 mins ask participants to feedback what good qualities they have noticed. Discuss importance of recognising and valuing positive qualities.</td>
<td>None</td>
</tr>
<tr>
<td>10.35</td>
<td>History and development of involvement</td>
<td>Give handouts on history. Show DVD &amp; discuss. Show slides on motivations. Discuss.</td>
<td>Open Up DVD presentation/OHT OHP/Dataprojector Handouts</td>
</tr>
<tr>
<td>11.35</td>
<td>COFFEE BREAK</td>
<td></td>
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</tr>
<tr>
<td>12.00</td>
<td>Why is involvement important?</td>
<td>Split groups into 2 – one representing</td>
<td>Flip chart &amp; pen presentation/OHT</td>
</tr>
</tbody>
</table>
su/c the other providers. Answer the questions
1. Why is invol impt for SU/C?
2. Why is invol impt for organisations
3. What are the differences in perspectives?
Feedback & discuss. Show slides
Give out handouts & policy

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Activity</th>
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<tbody>
<tr>
<td>1.00</td>
<td>LUNCH</td>
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<tr>
<td>2.00</td>
<td>Methods of Involvement</td>
<td>Split participants into small groups. Ask them to match cards on methods against the sheets with purposes. Then consider with other issues eg rural area, people in secure setting. Discuss</td>
</tr>
</tbody>
</table>
| 3.00 | Achieving Outcomes          | Line up 4 flipcharts with headings
Work from ‘where we would like to be?’ as brainstorm and ‘where we are now’.
Brainstorm obstacles. Turn obstacles into ‘how to’ statements.
Discuss need to identify and remove obstacles to find solution.
Brainstorm final flipchart question on knowing it has been achieved. Discuss need to evaluate outcomes. |
| 3.45 | Session evaluation          | Participants fill out sheets. Discuss                                    |
| 4.00 | Close                       |                                                                          |
Chapter 2 – Training Exercises

The following chapter contains all of the training exercises available to the trainer/facilitator of the training session to be undertaken.

Each of the exercises has one or more of the following symbols depicted next to the title of the exercise;

- ![People](image) Getting to Know Each Other, Energisers, Warm-ups and Finishers
- ![Heart](image) How to Involve Service Users and Carers
- ![Question Mark](image) Setting the Context of Involvement
- ![Film Reel](image) Developing Action

This will enable the facilitator to easily identify the exercise against the contents matrix, which will help when planning the training session.

The exercise goes on to give a brief description of the exercise, an overview of its objectives and a set of instructions for its delivery.

There are also relevant handouts provided.

The objective is to select a number of complementary exercises which will enable the facilitator to develop a balanced and informative training session, tailor made for the participants, addressing their specific training needs.
Exercise: Recognising the Positives

Brief Description
This exercise enables participants to get to know each other and recognise positive qualities.

Objectives
The purpose of this exercise is to:
- Enable participants to get to know each other and feel safe.
- Create a positive atmosphere where people can be open and honest.
- Get people talking to others.
- Introduce the need for positive affirmations and the power of compliments.

Preparation
None

Resources needed
Something to signal that five minutes have passed.
Time needed - approx 20 mins

How to run it
Let people know this is an opportunity to get to know someone they don’t know very well or don’t meet very often.

Ask participants to find the person they know least well. Explain that they have five minutes to tell the other person ‘what gives me purpose to what I do’ but not mentioning their work or job.

After 5 mins ask the person listening to feed back to their partners what qualities they have noticed in the person talking. E.g. personal qualities, skills, knowledge, experience. They have three minutes to do this.

Ask participants to swap roles.

Ask participants what this felt like.

Discuss the importance of recognising and valuing the positive qualities about people and ensuring people know you have noticed.

This is an important aspect when working with service users and carers who often believe that people only see their negative qualities. Giving people positive affirmations can help an individual’s feelings of self-worth and value.
Exercise: Discovering strengths

Brief Description
An icebreaker exercise that enables participants to get to know each other and to identify individuals differing strengths

Objectives
The purpose of this exercise is:
- For participants to get to know each other
- To explore the different strengths of individuals and groups
- To reflect on the need for groups to feel comfortable when working together particularly when involving service users and carers

Preparation
Cut out cardboard pieces 20cm X 30 cm for each participant
Photocopy handout ‘Animal Totems’
Time needed 25 mins

Resources needed
20cm x 30 cm cardboard sheet for each participant
Marker pens
‘Animal Totems’ handout
Sticky tape or blue tack

How to run it
Explain to participants that in the past, a totem pole was carved for several reasons; for example, to honour a deceased elder who was important to the carver, to show the number of rights and names a person had acquired over his or her lifetime, or to document an encounter with the supernatural. Today, totems are carved also to tell the story about the person commissioning the pole.

Ask the group to split into small groups of 3 or 4 and that they will each design a totem pole to discover the group’s strengths and weaknesses. Give each person a piece of cardboard and a list of totems. Ask them to design a figure that best represents their strengths in a group. They can use the symbols given or make up their own.

Explain that when each group has completed their drawing, each team will tape them one on top of the other on a portion of the wall. Also ask them to be prepared to explain their totem pole to everyone. Give them 15 minutes to complete

Finally suggest to the group that it is important to recognise strengths in people and groups. Also for people to feel comfortable to work together and this is particularly true when involving service users and carers. Exercises such as these can help people feel more comfortable to work together constructively and recognise everyone has differing strengths and abilities to offer.

(Adapted from Business Training Solutions 2002)
<table>
<thead>
<tr>
<th>Handout</th>
<th>Animal Totem Symbols</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alligator</td>
<td>Maternal and vengeful</td>
</tr>
<tr>
<td>Ant</td>
<td>Group minded, patient, active and industrious</td>
</tr>
<tr>
<td>Antelope</td>
<td>Active, agile, and willing to sacrifice</td>
</tr>
<tr>
<td>Badger</td>
<td>Courageous, aggressive, healing and energizing</td>
</tr>
<tr>
<td>Bat</td>
<td>Regenerative and long living</td>
</tr>
<tr>
<td>Bear</td>
<td>Industrious, instinctive, healing, powerful, sovereign, protective of the world and strong</td>
</tr>
<tr>
<td>Beaver</td>
<td>Determined, strong-willed, constructive and protective</td>
</tr>
<tr>
<td>Bee</td>
<td>Organized, industrious, productive, wise, social, celebratory, and enthusiastic about life</td>
</tr>
<tr>
<td>Buffalo</td>
<td>Sacred and strong</td>
</tr>
<tr>
<td>Butterfly</td>
<td>Metamorphic and transformative</td>
</tr>
<tr>
<td>Cat</td>
<td>Protective, detached, sensual, mysterious, magical and independent</td>
</tr>
<tr>
<td>Cheetah</td>
<td>Swift, insightful and focused</td>
</tr>
<tr>
<td>Cow</td>
<td>Nurturing and maternal</td>
</tr>
<tr>
<td>Crane</td>
<td>Solitary, just, enduring, independent, intelligent and vigilant</td>
</tr>
<tr>
<td>Crow</td>
<td>Law enforcing, shape shifting, changeable, creative, spiritual, energetic and just</td>
</tr>
<tr>
<td>Deer</td>
<td>Intellectual, gentle, caring, kind, subtle, graceful, feminine, gentle, innocent</td>
</tr>
<tr>
<td>Dog</td>
<td>Noble, faithful, loyal, trainable, protective, guiding</td>
</tr>
<tr>
<td>Dolphin</td>
<td>Kind, prudent, capable of deep emotion, wise and happy</td>
</tr>
<tr>
<td>Dragon</td>
<td>Enduring, infinite, wise, powerful and fiery</td>
</tr>
<tr>
<td>Eagle</td>
<td>Divine, sacrificing, intelligent, courageous, spiritually illuminated, healing, daring</td>
</tr>
<tr>
<td>Elephant</td>
<td>Strong, powerful and wise</td>
</tr>
<tr>
<td>Falcon</td>
<td>Adventurous, passionate and leading</td>
</tr>
<tr>
<td>Fish</td>
<td>Graceful</td>
</tr>
<tr>
<td>Fox</td>
<td>Cunning, agile, quick-witted, diplomatic, wild, feminine in its magic of camouflage, shape-shifting and invisibility</td>
</tr>
<tr>
<td>Frog</td>
<td>Cleansing, transformative, sensitive, medicinal, undiscernibly beautiful and powerful</td>
</tr>
<tr>
<td>Goose</td>
<td>Self-demanding, reliable, prudent, rigid, vigilant, parental, and productive</td>
</tr>
<tr>
<td>Hawk</td>
<td>Informative, intuitive, victorious, healing, noble, cleansing, visionary, and protective</td>
</tr>
<tr>
<td>Horse</td>
<td>Independent, enduring, mobile, terrestrial, powerful, and free</td>
</tr>
</tbody>
</table>
Jaguar - Chaotic and shape shifting
Lion - Family-oriented, strong, energetic, courageous and protective
Lizard – Conservalional and visionary
Llama - Comforting to others
Moose - Headstrong, enduring, steadfast and wise
Mouse - Observant, orderly, organized, and detail oriented
Otter - Playful, friendly, dynamic, joyful, helpful and generous
Owl - Deceptive, clairvoyant, insightful, informative, detached, wise, changeable and silent
Ox - Sacrificing and self-denying
Peacock - Immortal, dignified and self-confident
Rabbit - Fearful, timid, nervous, humble, fertile, intuitive, balanced and fertile.
Raven - Introspective, courageous, self-knowing, healing, protective, tricky and magical
Salmon - Proud, intense, confident, wise, inspiring and rejuvenating
Seahorse - Confident and graceful
Seal - Loving, desirous, imaginative, creative and dreamy
Shark - Predatory, enduring and adaptable
Skunk - Noticeably present and strong
Snake - Impulsive, shrewd, transformative, healing, energetic and wise
Squirrel - Organized and gathering
Stag - Sovereign, regenerative, giving of bounty, beauty and mystical signs.
Swan - Graceful, balanced, innocent, soulful, loving, beautiful, self-possessed
Tiger - Strong, valorous, powerful, energetic
Turkey - Generous, life-giving, self-sacrificing
Turtle - Nurturing, shy, protective
Weasel - Strong, energetic, ingenious, stealthy
Whale – Wise and giving
Wolf - Loyal, persevering, successful, intuitive, trainable, ritualistic and spirited
Woodpecker - Sensitive, protective and loyal

Cited from Business Training Works, Inc. 9015 Katie Court | Port Tobacco, MD 20677
www.businesstrainingworks.com
## Exercise: Responses to others

### Brief description:
An ice-breaker exercise to help people realise that how they respond to others is important

### Objectives
The purpose of this exercise is to:
- To enable participants to get to know each other
- To energise participants
- To consider that we all form perceptions about others and may respond to these inappropriately
- To reflect on the impact of our responses to others

### Preparation

### Resources
Space in a room for participants to move around easily
Sticky labels with words on
Time needed – about 10 mins

### How to run it
Allocate a label to each participant and stick it on their forehead without letting participants see what is written on the labels.

Ask participants to mill around each other responding to the label on each person’s head either verbally or through body language and expressions.

After about 10 mins bring participants together and go around to see what each participant thought was on their label. Check out to see if correct.

Have a quick discussion of the difficulty of percieving how people feel and the issue of responding to people in ways that are helpful and give the right message of caring and support.
Exercise: The continuum of health and ill health

<table>
<thead>
<tr>
<th>Brief description</th>
<th>An icebreaker exercise to enable participants to consider that there is a continuum between mental health and mental illness</th>
</tr>
</thead>
</table>

**Objectives**
The purpose of this exercise is:
- To enable participants to get to know one another
- To create a positive atmosphere where it is safe to share experiences
- To get people moving
- To enable participants to consider that mental illness does not have a dividing line between health and illness

**Preparation**
None

**Resources**
- Flip chart and paper
- Pens
- Room for participants to move around room to flipchart
- Time needed – around 10 – 15 mins.

**How to run it**
First go round the room asking people to say their names and in one word describe a word associated with being ‘mentally healthy’.

Then ask participants for *everyday* words that could describe someone they would consider has mental illness. For example ‘unhappy’ ‘tearful’ etc.

Write the words in lists down the flipchart. Encourage participants with ideas such as think of how you would know someone has anxiety or depression. When you have a fairly long list of words (if you have 10 participants then you have around 20 words) then ask participants to think about the words and to consider when they have felt the word has described them at some point in their life. Participants need to come up and cross off a word they can associate with at some point in their life. Keep taking turns until all the words have been crossed off.

Have a quick discussion following posing the question ‘what is the difference between mental health and mental illness?’.

It is important for participants to realise that there is not a dividing line between mental health and mental ill health. There is a continuum line which we all go along at various times. Also it is important to recognise that service user and carers are not seen as ‘different’ as anyone may struggle at times in their life.
Exercise   Respecting others opinions

**Brief Description**
A short exercise to create awareness of the need to work collaboratively in order to understand other people’s interpretations and opinions

**Objectives**
This purpose of this exercise is:
- To generate awareness that people can hold different interpretations to information or situations
- To explore the impact of different interpretations and opinions when involving service users and carers

**Preparation**
Photocopy ‘Interpretation’ handout
Photocopy ‘Interpretation answers’ handout

**Resources needed**
‘Interpretation’ handout
‘Interpretation answers’ handout
Time needed – approx 20 mins

**How to run it**
Give all participants a copy of the ‘Interpretation’ handout and ask them to read the short story and to spend 10 mins ticking the answers they believe to be correct.

Ask them to count up their scores on each column and tell them they should have a random spread of ticks. Tell them that apparently the only people to get it 100% right (so far) are people with an army background.

Now give them the answer sheets.

A discussion will probably follow. Suggest to the group that this example shows how we all interpret information or situations in different ways. Ask them to consider what impact this could have when involving service users and carers? Discuss.
Below is a story. Please read it and then you have ten minutes to record in the space provided beside each statement whether you think it is ‘true’, ‘false’ or ‘don’t know’. Mark with an ✓. Add up your scores in each column when you have finished.

A businessman had just turned off the lights in a store when a man appeared and demanded money. The owner opened a cash register. The contents of the cash register were scooped up and the man sped away. A member of the police force was notified promptly.

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TOTALS

(Phil Race)
Below is a story. Please read it and then you have ten minutes to record in the space provided beside each statement whether you think it is ‘true’, ‘false’ or ‘don’t know’. Mark with an ✓ or □. Add up your scores in each column when you have finished.

A businessman had just turned off the lights in a store when a man appeared and demanded money. The owner opened a cash register. The contents of the cash register were scooped up and the man sped away. A member of the police force was notified promptly.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A man appeared after the owner turned off his store lights</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>2. The robber was a man</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>3. The man who appeared did not demand money</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>4. The man who opened the cash register was the owner</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>5. The store owner scooped up the contents of the cash register and ran away</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>6. Someone opened the cash register</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. After the man who demanded the money scooped up the contents of the cash register, he ran away</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>8. While the cash register contained money, the story does not state how much</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>9. The robber demanded money of the owner</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. The robber opened the cash register</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. After the store lights were turned off a man appeared</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. The robber did not take the money with him</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. The robber did not demand money of the owner</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. The owner opened a cash register</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. The age of the store owner was not revealed in the story</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Taking the contents of the cash register with him, the man ran out of the store</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>17. The story concerns a series of events in which only three persons are referred to the owner of the store, a man who demanded money, and a member of the police force</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. The following events were included in the story, someone demanded money, a cash register was opened, its contents were scooped up, and a man dashed out of the store</td>
<td>✓ or □</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

**TOTALS** 4 1 or 2 12 or 13

(Phil Race)
Exercise: The history and development of Involvement

Brief description
An exercise to explain the history of involvement and to consider the different influences on the development of involvement.

Objectives
The purpose of this exercise is:
- To understand the context and history of why people get involved
- To learn about the developments within involvement
- To reflect on various motivations and expectations from different perspectives

Preparation
To have access to the Open Up Anti-Discrimination Toolkit Training Resource. Contact Mental Health Media 020 77008171
info@mhmedia.com
Prepare powerpoint presentation or overhead transparencies
Photocopy handouts

Resources
Open Up DVD – Clip no 1: Stand up for your rights
3 Slides – Stakeholder perspectives on motivations/expectations
Handout - History of involvement
Handout – Stakeholder perspectives on motivations/expectations
Powerpoint projector/laptop or overhead projector
Time needed – approx 1 hour

How to run it
Explain to participants that this exercise is to help them understand the history behind involvement within the context of other civil rights movements and to understand that there have been many motivations and expectations that have developed over the years from many different angles. It is important to recognise that there have been many influential factors, often with very different agendas for developing involvement

Give handouts on the history of the mental health service user movement and give a brief description.
Show the Open Up DVD (around 5 mins long)

Discuss what participants found useful from understanding this.

Show the 3 slides on ‘Stakeholder perspectives on motivations/ expectations of involvement’. Discuss as a group the different perspectives and how they may potentially conflict.
Handout: History of Service User Movement

Key developments in the mental health service user/survivor movement in England

1620 Petition of the Poor Distracted People in the House of Bedlam.
1845–63 The Alleged Lunatics’ Friend Society set up by John Perceval (forerunner of current advocacy groups).
1970s First anti-psychiatry groups (some are alliances between patients and professionals). Patient-only groups include Mental Patients’ Union and COPE (which later became EPOC, PROMPT and eventually CAPO – Campaign Against Psychiatric Oppression).
1980s Start of local user forums for mutual support and user involvement work.
1983–86 Forums set up in Hackney, Camden, Islington and other towns and boroughs. Often these are for service users and carers.
1985 MIND/World Federation for Mental Health conference: Dutch and US patient groups meet UK service user and survivor groups for first time.
1986 onwards media impact is made by the emerging movement: *We’re Not Mad We’re Angry* first TV programme/video led by survivors – highly critical of the biomedical model of mental illness: white and black survivors give their perspectives on mental health services. Many individuals speak out on radio, TV and in published articles.
1986–present National Voices Network formed within Rethink (formerly National Schizophrenia Fellowship - network of people with diagnosis of schizophrenia) for mutual support and recovery, and to eliminate stigma and misunderstanding. Peak membership 500.
1986 First patients’ councils and user-led advocacy projects set up: Early examples are Nottingham Advocacy Group and Hackney Patients’ Council.
1987 First national gathering of mental health service users/survivors from around the UK, at Edale event – run by Survivors Speak Out.
1988 Influential publications by service users/survivors emerge: A notable influence on the movement is *On Our Own* by Judi Chamberlin – an exploration of the rise of the survivor movement in the US. Numerous local publications and newsletters by service user/survivor groups begin to emerge, critically examining services and describing personal experiences.
1988–present The Hearing Voices Network (based on the work of Professor Marius Romme in Holland) began holding national events in 1990/91 and now has 100 groups across the country.
1990 NHS and Community Care Act first establishes requirement for service user involvement in community care planning.
1991 Emergence of networks and groups for survivor art, poetry and drama: a major network is Survivors’ Poetry, which runs workshops and performances, and publishes collections of survivor poetry.
1992–present  Service user-run services: Service user-run drop-ins established, including McMurphys in Sheffield and Brixton Community Sanctuary in Lambeth.  
1992  UKAN (UK Advocacy Network) established. Membership of service user/survivor-led groups, focus on advocacy. Over 300 groups currently affiliated.  
1992–94  Mental Health Task Force Service User Group (part of Department of Health’s Mental Health Task Force) set up. Produced publications: guidelines for service user charters and advocacy, ran a series of regional service user conferences and Training the Trainers events.  
In 1994, National Service User Conference in Derby, attended by over 200 service users representing the movement, endorses national charter and publications.  
1994–present  Black service users/survivors begin setting up separate groups and organisations: These include Awaaz in Manchester, Buddies in Bradford, and Share in Maudsley Black Action (SIMBA) and Black Women and Mental Health in London.  
1995–present  Service users/survivors as workers: Employment campaigns and programmes are developed by service users, including EcoWorks in Nottingham, and service user employment programme to support service users to find work within the South West London and St George’s NHS Trust.  
1996–present  User-led research – a number of programmes and projects are set up where research is led and carried out by service users/survivors: These include the User Focused Monitoring programme at SCMH, Strategies for Living at the Mental Health Foundation and Service User Research Enterprise (SURE) at the Institute of Psychiatry.  
1997–present  Service user/survivor-led innovations for self-managing mental health problems are developed by service users/survivors: Service user/survivor-led crisis projects emerge in Devon, Brighton, Birmingham, London, Wokingham, Corby, Leeds and elsewhere. Advance directives are developed as means of ensuring choice of treatment in crisis. Manic Depression Fellowship develops self management programme. The Strategies for Living project runs annual ‘Big Alternatives’ conferences, which become the focus for service user/survivor-led alternatives.  
1998  PACE service user/survivor-led report on gays’/lesbians’/bisexuals’ experiences of mental health services.  
1999  Reclaim Bedlam campaign (protest against the celebration of Royal Bethlehem Hospital anniversary), eventually leading to formation of Mad Pride, a group that organises demonstrations and celebrations of ‘mad culture’.  
2002  National Institute for Mental Health in England sets up service user and carer ‘Experts by Experience’ national consultative group.  
2003  Launch of On Our Own Terms: report from research on English service user/survivor movement  
2005  HASCAS Making a Real Difference Strengthening Service User and Carer Involvement in NIMHE  

(adapted from J Wallcroft, J Read, A Sweeney, 2003, On our Own Terms)
Motives and expectations of involvement in NHS

Central government

History of policies and directives:

- Introduction of Community Health Councils in 1974

- Consumerism policies (Griffiths Report, 1983; Working for Patients, 1988; NHS & Community Care Act, 1990; Local Voices, 1992)

- Partnership policies (NHSE Patient Partnership Strategy, 1996; NHS Plan, 2000)

- Recognition of carers’ input into health and social care (Carers’ Act 1995; Caring for Carers, 2000)

- Strengthening local accountability of NHS service providers: Section 11 of Health and Social Care Act 2001; Foundation Trusts(DH 2002) ; A Stronger Local Voice, 2006

- Improving the patient experience (DH 2002 – onwards)

(Crawford et al 2003)
Motives and expectations of involvement in NHS

**General public, service users and carers**

- Service users demand better services
- Campaign for citizens’ rights (at national and local level)
- Growth of public knowledge
- Growth of publicity on medical malpractice, shift away from ‘blind trust in experts’ (Barnes 1999)
- More influence demanded by involuntary service users (to reduce stigma and oppression) with service users identifying with new social movements resisting institutionalised oppression (Croft & Beresford 1992)
- Articulation of alternative models of disability and illness (Crawford et al 2003)
Motives and expectations of involvement in NHS

Managers, Clinicians and Commissioners

- In order to facilitate public health initiatives such as mass vaccination (Rifkin 1981)

- Emphasis on better management and quality control within the NHS: patients can identify poor practice (Coulter 2002)

- Recognition that patients can be ‘co-producers’ of their health (Calnan et al 1998) so health outcomes can be improved

- Service user involvement diffuses responsibility for difficult decisions, may be used to legitimise preferred options of other stakeholders (Cooper et al 1995, White 2000)

- Service user involvement provides a new way of legitimating decisions about funding in an era of resource constraints (Burns-Tisdale et al 1994)

- Legislative requirement to implement central government directives on user involvement (Crawford et al 2003)
Handout: Stakeholder perspectives
Motives and expectations of involvement in NHS

Central government

History of policies and directives:

- Introduction of Community Health Councils in 1974
- Consumerism policies (Griffiths Report, 1983; Working for Patients, 1988; NHS & Community Care Act, 1990; Local Voices, 1992)
- Partnership policies (NHSE Patient Partnership Strategy, 1996; NHS Plan, 2000)
- Recognition of carers' input into health and social care (Carers' Act 1995; Caring for Carers, 2000)
- Strengthening local accountability of NHS service providers: Section 11 of Health and Social Care Act 2001; Foundation Trusts(DH 2002); A Stronger Local Voice, 2006
- Improving the patient experience (DH 2002 – onwards)

General public/service users/carers

- Service users demand better services
- Campaign for citizens’ rights (at national and local level)
- Growth of public knowledge
- Growth of publicity on medical malpractice, shift away from ‘blind trust in experts’ (Barnes 1999)
- More influence demanded by involuntary service users (to reduce stigma and oppression) with service users identifying with new social movements resisting institutionalised oppression (Croft & Beresford 1992)
- Articulation of alternative models of disability and illness etc

Managers, Clinicians and Commissioners

- In order to facilitate public health initiatives such as mass vaccination (Rifkin 1981)
- Emphasis on better management and quality control within the NHS: patients can identify poor practice (Coulter 2002)
- Recognition that patients can be ‘co-producers’ of their health (Calnan et al 1998) so health outcomes can be improved
- Service user involvement diffuses responsibility for difficult decisions, may be used to legitimise preferred options of other stakeholders (Cooper et al 1995, White 2000)
- Service user involvement provides a new way of legitimating decisions about funding in an era of resource constraints (Burns-Tisdale et al 1994)
- Legislative requirement to implement central government directives on service user involvement


Resource Pack for Trainers and Facilitators
2007
Exercise: Why is Involvement important?

**Brief Description**
This exercise explores why involvement is important from a range of perspectives and to consider potential outcomes.

**Objectives**
The purpose of this exercise is:
- To analyse why involvement is important
- To analyse why organisations need to involve people
- Understand some beneficial outcomes from involvement

**Preparation**
- Photocopy handouts
- Prepare slides
- Write questions on flipchart

**Resources needed**
- Flipchart & pens
- Flipchart paper
- Powerpoint dataprojector/OHP
- CSIP/NIMHE Policy on Involving Service Users and Carers
- Slides ‘Why is involvement important?’
- Slide ‘In the public interest’
- Slide ‘Aims of public involvement’
- Handouts ‘Why is involvement important?’ & ‘What are the benefits of Involvement?’
- Time needed – 1 hour

**How to run it**
Split the participants randomly into two types of group – one to represent service users and carers and the other to represent providers. (Split these two groups into similar smaller groups if necessary).

Ask the groups to answer the following questions from the perspective of either being a service user or carer (they can choose which) or provider. Give them 30 minutes to write answers onto flipchart paper.

- Why is involvement important for service users or carers?
- Why is involvement important for organisations providing services?
- What are the differences between the service user or carer and provider perspectives on involvement?

Lead a feedback from each group and have a discussion around the issues raised.
Exercise: Why is Involvement important?

How to run it (continued)

Show slides 1 & 2 ‘why is involvement important’ and discuss how involvement can alter and benefit the information and knowledge for all concerned.

Show the slide 3 ‘Why involve service users and carers’ and discuss that involvement is sometimes explained or justified in terms of the benefits to individuals. However this slide presents a rationale encompassing outcomes for the health service, its users, public health and local communities.

Show slide 4 ‘Broad reaching aims of public involvement’ and discuss.

Give out handouts and CSIP/NIMHE (or own organisational) policy on involvement asking participants to read through it and ask questions if necessary.
Why is involvement important?

*Involvement increases the amount of shared knowledge. Service users and carers share the knowledge previously known only to them and so do providers.*

**Before Participation**

<table>
<thead>
<tr>
<th>What service users and carers know</th>
<th>What service users and carers do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everybody knows</td>
<td>Services know, service users do <strong>not</strong> know</td>
</tr>
<tr>
<td>Service users know, Services do <strong>not</strong> know</td>
<td>Nobody knows</td>
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</tbody>
</table>
After participation

<table>
<thead>
<tr>
<th>What the service knows</th>
<th>What service users and carers know</th>
<th>What service users and carers do not know</th>
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<tr>
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Based on the Johari window,

Why involve service users and carers?

Benefits to the NHS

• Restoration of public confidence
• Improved outcomes for individuals patients
• More appropriate use of health services
• Potential for greater cost-effectiveness
• Contribution to problem resolution
• Sharing responsibilities for healthcare with the public

Benefits to people

• Better outcomes of treatment and care
• An enhanced sense of self-esteem and capacity to control their own lives
• A more satisfying experience of using health services
• More accessible, sensitive and responsive health services
• Improved health
• A greater sense of ownership of the NHS

Benefits to public health

• Reduction in health inequalities
• Improved health
• Greater sense of understanding of the links between health and the circumstances in which people live their lives
• More healthy environmental, economic and social policies

Benefits to communities and to society as a whole

• Improved social cohesion
• A healthier democracy – reducing the democratic deficit
• A health service better able to meet the needs of its citizens
• More attention to cross-cutting policy issues and closer co-operation between agencies with a role to play in health improvement

(Dept of Health 1998 In the public Interest: developing a strategy for public participation in the NHS)
Broad-reaching aims of Public Involvement

- **Governance**: e.g promoting active citizenship

- **Social cohesion and social justice**: eg building social capital and empowerment

- **Improved quality of services**: eg encouraging appropriate and effective use of public services

- **Capacity building and learning**: eg as a basis for future growth and development

(Involve and togetherwecan 2006)
**Handout 1: Why is involvement important?**

As the following model illustrates, participation increases the amount of shared knowledge. Service users share the knowledge previously known only to them and so do providers.

**Public participation model**

**Before Participation**

<table>
<thead>
<tr>
<th>What the service knows</th>
<th>What service users and carers know</th>
<th>What service users and carers do not know</th>
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<td>Service users know, Services do not know</td>
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</table>

**After Participation**

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<tr>
<th>What the service knows</th>
<th>What service users and carers know</th>
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</table>

Handout 2: What are the benefits of involvement?

In the public interest: developing a strategy for public participation in the NHS
(Department of Health 1998)

Benefits to the NHS
- Restoration of public confidence
- Improved outcomes for individuals patients
- More appropriate use of health services
- Potential for greater cost-effectiveness
- Contribution to problem resolution
- Sharing responsibilities for healthcare with the public

Benefits to people
- Better outcomes of treatment and care
- An enhanced sense of self-esteem and capacity to control their own lives
- A more satisfying experience of using health services
- More accessible, sensitive and responsive health services
- Improved health
- A greater sense of ownership of the NHS

Benefits to public health
- Reduction in health inequalities
- Improved health
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- Improved social cohesion
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Broad-reaching aims of Public Involvement
(Involve and togetherwecan 2006)
- Governance: e.g promoting active citizenship
- Social cohesion and social justice: e.g building social capital and empowerment
- Improved quality of services: e.g encouraging appropriate and effective use of public services
- Capacity building and learning: e.g as a basis for future growth and development
Exercise: Levels of Involvement and increasing power

Brief description
By using the ladder of citizen participation this exercise explores the different levels of involvement

Objectives
The purpose of one of these exercises is:
- To provide understanding of different degrees of involvement
- To consider the complexities of involving people in meaningful ways
- To reflect on current working practices in terms of involving people
- Consider how service users and carers can hold greater power

Preparation
For exercise 5 make a ladder from cardboard

Resources
Slide/Handout – Ladder of Participation
Handout – scenarios of different levels of involvement
Time needed – 30 – 45 mins

How to run it
Ask participants to form small groups of 4 – 6 and explain that this exercise is to enable them to think about different levels of involving people through using the ‘Ladder of Participation’.
A variety of exercises can be used for this:

Exercise 1
Explain the ladder and how it relates to the involvement of people who use services and the people that support them.
Provide scenarios of different levels of involvement from the handout Ask people in groups to identify where the scenario sits on the ladder, discussing the reasons for this decision and how this could be improved so that the scenario may sit higher up the ladder.

Exercise 2
Ask groups to review the different scenarios of involvement and identify the:
- Best opportunities for involvement
- Worst opportunities for involvement
Exercise: Levels of involvement and increasing power

How to run it continued

Exercise 3
Ask groups or individuals to develop scenarios themselves.

Exercise 4
Ask groups or individuals to write a scenario that only fits on one part of the ladder (this is almost impossible, highlighting the complexity)

Exercise 5
To explore the ladder of involvement with a group of 8 or 9 people, a more practical exercise can be used. Parts of the ladder made out of cardboard, can be cut out and placed on the floor, scenarios written out can then be discussed as a group, with one person placing the scenario on the ladder where it is appropriate.

(CSIP Service Improvement Guide)
Ladder of Participation

8. Citizen control
7. Delegated power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Degrees of citizen power

Degrees of tokenism

Non participation

Arnstein S (1969) A Ladder of citizen participation in the USA
The ladder of citizen participation is a model used to examine degrees of involvement of participation. It can therefore be used to explore degrees of involvement of people who use services and the people that support them.

**About the model**

In 1969, Sherry Arnstein wrote about citizen involvement in planning in the United States. She described a ladder of involvement, to highlight that there are different levels of involvement. This ladder is outlined below:

<table>
<thead>
<tr>
<th>8. Citizen control</th>
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<tr>
<td>7. Delegated power</td>
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<tr>
<td>6. Partnership</td>
</tr>
<tr>
<td>5. Placation</td>
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<tr>
<td>4. Consultation</td>
</tr>
<tr>
<td>3. Informing</td>
</tr>
<tr>
<td>2. Therapy</td>
</tr>
<tr>
<td>1. Manipulation</td>
</tr>
</tbody>
</table>

1. **Manipulation** and 2. **Therapy**. These levels are non participative. They focus on “educating” or “curing” the participants. The stance at this level is that the proposed plan is best and the job of participation is to gain public support.

3. **Informing**
   
   This can be the first important step to legitimate participation; however too often there is an emphasis on a one-way flow of information, with no feedback mechanism or negotiation power, giving people little opportunity to influence.

4. **Consultation**
   
   Inviting opinions can be another legitimate step to participation; however there are no guarantees that the information gained from the consultation will be taken into account, and can be seen as a “window dressing ritual”.

---

Handout: Ladder of Participation

Degrees of citizen power

Degrees of tokenism

Non participation

Resource Pack for Trainers and Facilitators

2007
5. *Placation*
This allows participants to advise and be involved though the power holders have the continued right to decide.

6. *Partnership*
This is where power is redistributed though negotiation between the citizens and power holders. The planning and decision-making responsibilities are shared between them, examples of these are joint boards and joint committees.

7. *Delegated power*
This is where the citizens are the dominant decision makers, enabling the citizens to assure accountability of the programme to them. For example, they may have the majority of seats on a committee or board

8. *Citizen control*
This is where the citizens are in charge or control of the whole programme; planning, policy-making and implementation.
Handout 2: Scenarios of different levels of involvement

Listening to the way people that use services see services.

Circulating a development plan to people that use services for their comments.

Telling someone about their medication.

Explaining to someone why their demands cannot be met.

Presenting options to people that use services which the nurse feels are most appropriate - not necessarily all the options available.

Asking someone to sign a care plan written for them by a nurse.

Working with someone to produce an agreed care plan.

People that use services contributing to programmes and the delivery of staff training.

Sending out service devised satisfaction questionnaires.

People that use services monitoring the performance of services by talking to other people that use services (in a planned way).

Devising information sheets with people that use services.

Paying people that use services for their time spent on a piece of work for the service.

Giving someone an information pack when they start to use a service.

Taking information about services out to existing groups of people that use services.

Representation of people that use services in a group that makes policies for the whole organisation.

Changing someone’s care plan without discussion.

Asking a person using services if their experience can be used as a case study.

People that use services on a committee which they have no decision making power.

Supporting a person that use services that you feel is being ambitious about what they can achieve.
Handout 2: Scenarios of different levels of involvement

When the person that uses services views are in conflict with the nurse recording them in case notes.

Making sure there is representation of people that use services on a group, as the funders require this.

People that use services as equal members of an interview panel for new staff.

Providing representatives of people that use services with training, such as committee skills and research skills.

Providing resources for people that use services to organise a conference.

Providing information in Braille or large print or their own language.

Informed representation of people that use services on a multi-agency steering group.

Service providing venues for groups of people that use services to meet.

Using non-verbal body language to influence a person’s (that use services) choice when decision-making.
### Brief Description
An exercise for participants to explore planning involvement strategies in order to achieve effective outcomes.

### Objectives
This exercise is to:
- Explore planning a process of service user and carer involvement in new work
- Consider the issues at each stage
- Examine what needs to be considered to foster effective involvement

### Preparation
Write headings onto 4 flipchart sheets and stick on walls
Photocopy handouts
Prepare slides
Read background information

### Resources needed
Flip chart paper and pens
Stick it note paper
Powerpoint data projector/OHP
Background info ‘Process of Involvement’
Slides: ‘How to get good outcomes’
‘Different approaches’
‘Different type of group member’
Handouts ‘Factors to consider when planning involvement’
‘Developing a strategy’
Time needed – 45 mins - 1 hour

### How to run it
Discuss with whole group the importance of following a good involvement process which is more than just limited to deciding from a choice of methods. (see background info ‘Process of Involvement’)

Show the slide ‘Planning involvement’ and highlight the importance for any new project of involving people that the purpose is clearly agreed by all stakeholders and the context and any history is carefully considered. Then the process including a choice of methods needs to be planned and agreed. (see background info)

Show the slide ‘Different approaches’ to involvement and discuss that for some service users and carers they prefer to influence services by working within the system whereas for others they prefer to develop their own alternative services.
Exercise: Involvement Strategies

How to run it (Continued)

Discuss and show the slide of different types of group member (see background info) and explain that people become involved for many differing reasons and this needs to be taken account of when thinking of what people need or want to do within their involvement.

Ask people to consider if they were starting a new project which needed to involve people to consider all the different elements a strategy may need to consider. For example identifying resources or giving feedback. Give all participants around 20 stick-it notes and ask them to write down what they consider key elements.

Have four flip charts sheets stuck on wall with headings:
Stage 1 Find participants
Stage 2 Make participation meaningful
Stage 3 Build confidence and trust
Stage 4 Remain accountable

Ask participants to stick their points under each heading.

Give participants 15 – 25 minutes to complete. Hold a whole group discussion on what people felt was really important and also to discuss any elements they had not considered before and why this was.

Give the handouts ‘Factors to consider when planning involvement’ and ‘Developing a Strategy’
Background Information: Planning Involvement

Too often discussion of participation is limited to the methods used. Whilst the choice of methods is an important element they are only one part of involvement processes. With all front lines, their effectiveness is determined by the quality of planning and the planning of how to handle the results and links into wider decision making processes and systems.

Purpose + Context + Process = Outcomes

Purpose.
It is essential to be clear of what the involvement process aims to achieve. Ideally this purpose needs to be agreed by all participants. The nature of the purpose will contribute to the choice of methods. There are many purposes for participation particularly within representation such as:

- Involve and engage
- Explore issues and come up with new ideas
- Network and share ideas and practices
- Make decisions
- Inform

Context.
The context will vary with each situation and have influencing factors such as the issues, history, the people, the organisation and institutions taking part. These factors will influence the choice of methods.

Process.
Any form of involvement process needs to plan how the purpose will be achieved including which methods to use. The design of the process should follow agreement on purpose. ‘Form follows function’.

All methods have their strengths and weaknesses but the key is to ensure those chosen are correct for the particular purpose and context. Methods have developed from a variety of different fields and tend to produce certain outcomes. For example those from marketing such as focus groups are good at identifying needs. The facilitator and their background will also impact on the approach and the outcomes.

Therefore any discussion on involvement that focuses on methods alone will be misleading and unsuccessful for both those organising and those participating.

Outcomes
Outcomes are the fundamental difference that a process makes with its results and impacts. Outcomes are more specific than ‘purpose’ and are a clear statement of what is sought from the process. Possible outcomes include:
Background Information: Planning Involvement

- Improved personal and working relationships
- Wider circle of responsibility for decisions and actions
- Agreement on purpose and direction of a project or policy
- Identification of issues, benefits and drawbacks
- Generation of new ideas
- Policy change
- Cost savings
- Improved services for people
- Behaviour change

(Involve (2005) People and Participation. How to put citizens at the heart of decision making)

Methods by level

Individual care – treatment and self management. Making use of written and verbal information to inform treatment choices and likely outcomes. Information needs to be presented at the right time, by the right people, in the right circumstances.

Within health or social care services. People can be involved as individuals who have experienced a particular service or they can represent others.

Larger system wide/societal level. Involvement at this level usually occurs through people who can represent the views of others.

Group membership

Within any participation group there will be people joining for differing reasons and often encouraging ‘mass participation’ is not always the best approach for any group especially in the early stages. However many groups do recognise the need to mobilise a wider cross-section of people.

Looking at participation within the area of having effective governance Birchall and Simmonds (2004) cite members as falling into three types:

- Type 1 - The ‘true believers’ who can be persuaded to serve as active representatives on formal governance structures.
- Type 2 - Those who can be formed into a kind of ‘supporters club’ who believe in the aims of the organisation and will participate in governance through voting, attending annual meetings or social events
- Type 3 - Those ‘concerned un-mobilised’, who believe in the ethos of the organisation, will not participate in governance structures, but want to be kept informed and to have their views canvassed occasionally.

Planning Involvement

Purpose + Context + Process = Outcomes
Different Approaches to Involvement

• *From the ‘Inside’*

‘Consumer Involvement’. Acting as an individual or as part of a group with representatives linking into the PCT, Trusts, CSIP etc. Sitting on management committees, writing views, monitoring and evaluation of provider service, working for the organisation etc.

• *From the ‘Outside’*

‘Democratic Involvement’. Creating alternative service user or carer led services, pressure groups, campaigning, Self help groups.
Types of service user and carer organisational group member

- **Type 1** – The ‘true believer’ who can be persuaded to serve as active representatives

- **Type 2** – The ‘Supporters Club’ who believe in aims of organisation and will participate through voting, attending meetings, social events etc

- **Type 3** – The ‘concerned un-mobilised’ who believe in ethos of organisation but just want to be kept informed and not participate

(Birchall and Simmonds 2004)
Handout: Factors to consider when planning involvement

1 Be clear about the aims and scope of involvement before contacting service users and carers.
Is the primary aim of involvement to improve accountability, improve satisfaction with care, service utilisation or are there other aims? Ensure that there is scope for service users and carers to influence services before consulting them. Clarify the extent to which services can be changed on the basis of service user views; are resources available to implement service user views?

2 Make the aims and scope of involvement clear to service users and carers who participate.
Service users and carers should be told how they can contribute to change and the basis on which decisions on whether or not to implement changes suggested by service users will or will not be made: Are resources available to support the implementation of suggestions from service users and carers? Do requirements of central government or other bodies, or health improvement priorities and targets, mean that some elements of change are non-negotiable?

3 Ensure that there is organisational commitment to act on the views of service users and carers before involvement begins.
The impact that service users and carers have will depend less on the methods of involvement than on the willingness of decision makers to act upon the advice and suggestions that service users generate.

4 Before embarking on new involvement initiatives find out what has already taken place.
Experience of previous local involvement will help in planning and implementation of new initiatives.

5 Ensure that involvement is responsive to the aims and demands of local service users and carers.
Successful involvement needs to be bottom-up as well as top-down and the commitment of local service users to achieving the changes they want will facilitate successful involvement. As well as issues service providers want to consult on, is there capacity for service users and carers to introduce concerns?

6 Make sure that there is adequate time and resources to support involvement.
Involvement may make the decision-making process slower and more costly.

7 Consider how feedback will be presented to service users who participate.
Service users and carers are unlikely to make a sustained contribution to involvement unless their involvement results in visible and meaningful changes to services. If change is hampered, participants must be told why.
8 Consider how important the representation of service users and carers who participate is to the process of involvement.
Is representation important? Asking ‘why?’ should help you arrive at suitable strategies for accessing a range of views. Combining different methods will allow a greater range of people to be involved than relying on a single method. Avoid criticising people for not being ‘representative’.

9 Ensure that adequate information, time, administrative and financial support is available.
Discussing the needs of the people who contribute to the process will maximise their ability to contribute to the process of change. Will involvement be equally accessible and comfortable for people of black and minority ethnic backgrounds? Will expenses be paid and support and training offered?

10 Ensure that staff involved in the process are committed to making it a success
Staff involved may be ambivalent about the value of involvement. Defensiveness on the part of service providers can damage involvement initiatives. Staff training may be required; finding ways to make staff feel their views are also influential may be even more important.

### Developing an umbrella strategy

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
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<tbody>
<tr>
<td>Identify mobilisation potential</td>
<td>Make participation meaningful</td>
<td>Build confidence and trust</td>
<td>Remain accountable</td>
</tr>
<tr>
<td>1. Identify potential participants</td>
<td>1. Review structures and opportunities for</td>
<td>1. Reinforce the key values and benefits of</td>
<td>1. Make accountability central to participatory governance</td>
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<tr>
<td>(example, update databases, hold</td>
<td>participation</td>
<td>participation</td>
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<td>event or consult.)</td>
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<tr>
<td>2. Conduct research with potential</td>
<td>2. Provide clear, relevant information to</td>
<td>2. Engage widely and responsibly with all</td>
<td>2. Reinforce the importance and value of</td>
</tr>
<tr>
<td>participants</td>
<td>participants.</td>
<td>interested service users.</td>
<td>participation in governance</td>
</tr>
<tr>
<td>3. Remove or minimise barriers to</td>
<td>3. Recruit or select ‘type 1’ members to</td>
<td>3. Ensure wider service user community gets</td>
<td>3. Ensure that structures for participation</td>
</tr>
<tr>
<td>participation</td>
<td>task-oriented roles</td>
<td>regular feedback</td>
<td>are continually renewed and therefore seen</td>
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<td>as legitimate</td>
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<td>4. Engage ‘type 2’ and ‘type 3’</td>
<td>4. Ensure effective arrangements for</td>
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<td>members as creatively as possible</td>
<td>succession put in place</td>
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<tr>
<td>5. How do service users evaluate</td>
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<td>these opportunities?</td>
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<td>5. Ensure accountability to wider</td>
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<td>group membership</td>
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Exercise:  Good practice and encouraging involvement

**Brief description**  
A small group exercise that will enable participants to consider why people choose to get involved and develop good practice to continue to support this.

**Objectives**  
The purpose of this exercise is:  
- To explore different motivations and incentives of why people get involved  
- To consider the necessary variables that may encourage people to participate  
- To consider good practice for organisations to follow when involving service users and carers

**Preparation**  
Prepare slides  
Photocopy handouts  
Background reading

**Resources**  
Dataprojector/OHP  
Flip chart and pen  
Handout and background reading ‘Why do people participate or not?’  
Copies of NIMHE/CSIP Good Practice Guidance  
Slide ‘Why do people participate?’  
Slide ‘Good Practice Guidance’  
Time needed approx 1 hour 15 mins

**How to run it**  
Ask participants to think of all the things they value in life. Write the answers onto a flipchart. (for example, friends, job etc.)

When you have a long list now ask the participants to imagine that they have developed mental health difficulties and have become seriously unwell, have spent a period of time in an inpatient on an acute ward and have been detained under the Mental Health Act.

Ask participants to look at the list on the flip chart and to get up and cross off one word that they feel would be negatively effected or lost now.

When all or most of the words have been crossed off then state to the group that this is often the starting point for people who get involved when they may have lost a lot of things in their life that they had previously.
Exercise: Good practice and encouraging involvement

How to run it continued

Ask people to discuss in small groups for 20 mins
1. The reasons why people choose to participate.
2. What could encourage people to participate
3. What are important aspects an organisation should consider when involving people?

Feedback answers fairly quickly (without long discussion) and write onto flipchart.

Follow on with a short presentation and discussion for around 20 minutes on issues around motivations of people to participate. (see handout for info)

Show the slide and give handout on ‘Why do people participate?’ and discuss (see handout for info)

Give participants the CSIP/ NIMHE ‘Good Practice Guidance’ and briefly talk through the key points asking people to tick those they have mentioned on their flip chart paper. Ask them to read it all properly once at home and to refer to within work practice.
**Why do people participate?**

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<tr>
<th>Collective incentives</th>
<th>Sense of community</th>
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<td></td>
<td>Shared values</td>
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<td></td>
<td>Shared goals</td>
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<td>Individual incentives (internal)</td>
<td>Chance to have my say</td>
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<td></td>
<td>Learning experience</td>
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<td></td>
<td>Sense of achievement</td>
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<tr>
<td>Individual incentives (external)</td>
<td>Enjoyment</td>
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<tr>
<td></td>
<td>Getting my problem solved</td>
</tr>
<tr>
<td></td>
<td>Social life</td>
</tr>
</tbody>
</table>

Good Practice Guidance

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

(Care Services Improvement Partnership 2006)
Handout: Why do people participate?

There is controversy in social psychology between those who see people as innately competitive or co-operative (Argyle 1991).

One theory that has been developed is ‘Mutual Incentives Theory’ (MIT) of motivations to participate. This has two approaches:

The individualistic approach which asks ‘what do I get out of it’. This assumes people are motivated by individual rewards and consider the costs and benefits to themselves.

The collectivistic approach interpretes behaviour differently and assumes three variables as motivating factors:

- Shared goals: people express mutual needs that translate into common goals
- Shared values: people feel a duty to participate as an expression of common values
- Sense of community: people identify with and care about other people who live in the same area or are like them in some respect.

This approach generalises that the more that each of these variables are present then the more likely people will participate.

Other important aspects that influence people to participate are the availability of resources including time, money, skills and confidence. Creation and promotion of opportunities to participate that are relevant, timely and attractive are important factors.

People have their own styles and strategies which are employed with service providers. They may be ‘defenders’ or ‘protesters’ Piette (1990) or ‘insiders’ or ‘outsiders’ (Maloney et al 1994). The experience they have also influences – if they have a positive experience they may become more committed to participate and attitudes of the providers and organisers plays a big part in these dynamics.

For successful promotion of participation there is a strong participation chain needed. This metaphor is important as each ‘link’ in the chain has to be made as strong as possible if participation is to be strengthened.

The Participation Chain

Level 1 Resources-------Level 2 Mobilization-------Level 3 Motivations-------Level 4 Dynamics

- To strengthen resources, action must focus on building up skills and confidence through tools such as training and advocacy
- To strengthen mobilisation, important tasks include facilitating discussion of the issues that are important to service users; keeping a balance between ‘task oriented’ and more ‘social’ activities and ensuring that people get asked directly to participate
Handout:  Why do people participate?

- Strengthening the motivations link involves appealing to people’s dominant motivations and ensuring participation processes work with the grain of what matters to them, rather than against it.
- If the dynamics link is to be strengthened there is a need for providers to understand and communicate their own motivations, manage expectations of others and provide effective feedback.

Also importantly the links must be connected effectively if participation is not to fail. For example there is no point in training people in the necessary skills unless opportunities are going to be provided to use those skills.

Exercise: Methods of Involvement

**Brief Description**
A small group exercise that will enable participants to consider the use of appropriate methods.

**Objectives**
The purpose of this exercise is:
- To consider how to effectively plan participation
- To explore a range of different methods in relation to different purposes and contexts
- To consider how differing factors and client groups impact on the choice of methods

**Preparation**
Prepare Methods of Involvement’ cards by printing out and cutting out the squares for each group
Prepare Purpose cards by writing each individual ‘purpose’ on A4 sheets and give a set to each group
Photocopy handout

**Resources needed**
Pack of ‘Methods of Involvement’ cards for each group
Purpose of Involvement sheets
Handout – Methods of involvement in public sector healthcare
Time needed – 1 hour

**How to run it**
Explain to participants there are many different methods but these have to be considered within the overall planning of any involvement. So the purpose must be considered, the context of involvement and any history as well as develop a process which includes an appropriate method. Getting all these things in place should help achieve the desired outcomes.

Put participants into groups of 3 – 4 and give each group a set of sheets titled ‘Purpose’. Then give them another set of small coloured cards with lists of possible methods. Ask them to spend 20 minutes placing the various methods onto the relevant purpose sheets.

Then ask them to consider and discuss in their group for 20 minutes how different issues may affect their choice of methods.
1. covering a rural area or inner city,
2. focusing on a service for children and young people
3. focusing on a secure setting
4. focusing on people with dementia
5. focusing on people with a learning disability

Following this have a whole group discussion on what each group felt about this task and what they had learnt. Give out methods handout.
<table>
<thead>
<tr>
<th>Complaints</th>
<th>Question and answer session</th>
<th>Public meetings</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshops</td>
<td>Forums</td>
<td>Surveys</td>
<td>Consult local organisations</td>
</tr>
<tr>
<td>Consult support groups</td>
<td>Opinion polls</td>
<td>Phone ins</td>
<td>Advocates</td>
</tr>
<tr>
<td>Use involvement representatives</td>
<td>Use bilingual workers</td>
<td>Find culturally appropriate places</td>
<td>Prepare translated Information</td>
</tr>
<tr>
<td>Online Forums/websites</td>
<td>Service satisfaction surveys</td>
<td>Project groups</td>
<td>In-depth interviews</td>
</tr>
<tr>
<td>Focus groups</td>
<td>Consultation documents</td>
<td>Patient forums</td>
<td>Group techniques</td>
</tr>
<tr>
<td>Promotion</td>
<td>Campaigns</td>
<td>Workshops</td>
<td>publications</td>
</tr>
<tr>
<td>Resource Type</td>
<td>Public meetings</td>
<td>Seminars</td>
<td>Conferences</td>
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<tr>
<td>Research</td>
<td>Evaluations</td>
<td>In-depth interviews</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Community plans</td>
<td>Support groups</td>
<td>One to one</td>
<td>Patient councils</td>
</tr>
<tr>
<td>Service user groups</td>
<td>Carer groups</td>
<td>Representatives</td>
<td>Youth empowerment</td>
</tr>
<tr>
<td>Consultative committees</td>
<td>Service user/carer involvement policies</td>
<td>Input into organisational policies</td>
<td>Community groups</td>
</tr>
<tr>
<td>Question lists</td>
<td>Care plans</td>
<td>Assessment tools</td>
<td>Education classes</td>
</tr>
<tr>
<td>Committee work</td>
<td>Specific information</td>
<td>Skills training</td>
<td>Tailored information</td>
</tr>
<tr>
<td>Reference groups</td>
<td>Social events</td>
<td>Social meeting places</td>
<td>workshops</td>
</tr>
</tbody>
</table>
On separate sheets A4 write each heading and photocopy enough copies for each group

1. IDENTIFY RISKS OR PROBLEMS

2. ENGAGE CULTURALLY DIVERSE SERVICE USERS AND CARERS

3. IDENTIFY PRIORITIES OR NEEDS FOR COMMUNITY

4. PROVIDE INFORMATION AND SEEK VIEWS ON A NEW SERVICE

5. MEASURE ACCEPTABILITY OF SERVICE

6. PLAN HEALTH OR SOCIAL CARE SERVICES

7. FACILITATE INDIVIDUAL CARE
Methods of involvement in public sector healthcare

Methods through which users are involved

Initiated by service providers

- Time limited

Research methods
- Surveys
- Interviews
- Focus groups
- Rapid appraisal

Deliberative Approaches
- Citizens juries
- Public conferences
- Deliberative polling

Initiated by service users

Other Methods
- Employing service users and carers
- Media
- Audit
- Service User-focused monitoring
- Staff appointments
- Staff training

Ongoing relationships

With Service user or Community groups
- Service User groups*
- Local health panels
- Other groups

With formal bodies
- Patients groups
- Advocates and link workers
- Committee representatives

* Service user and carer groups and service user and carer-led services have been initiated by both service providers and service users

Exercise: Involving Diverse Groups

**Brief Description**
An exercise which encourages participants to consider issues around the involvement of less well represented groups.

**Objectives**
The purpose of this exercise is:
- To understand the principles behind involving less well represented groups
- To explore a range of considerations for different types of groups when organising meetings or events to meet their needs
- To highlight the importance of putting into practice the guidance on involving diverse groups

**Preparation**
Photocopy handouts
Prepare slides
Read background information

**Resources needed**
- Powerpoint dataprojector/Overhead
- Flip chart and paper and pens
- Handouts ‘Engaging Diverse Groups and Communities’ Making a Real Difference
- Time needed – 45 mins

**How to run it**
Explain to the participants that this session is about involving those groups which are often less well represented.
Ask the group for ideas of who these groups of people may be. Write the answers onto a flipchart. Some prompts might include, service users who are not members of forums, service users who avoid services.
Discuss the issues on background info and show the slides on;
‘Overarching principles’
‘Minimum standards are not about’
‘Minimum standards’
Inform participants that they will be given a handout at the end of the session which gives them much more detail of these minimum standards.
Exercise: Involving Diverse Groups

How to run it (Continued)

Suggest to participants that when planning an event or meeting there are considerations to be made when involving service users and carers particularly if the event is to be fully inclusive and accommodate all needs.

Ask the participants to get into small groups of 3 or 4 and give them each a different diverse group or community to consider. If small numbers of participants it may be necessary for each group to consider more than one type of diverse group or community. Give each group a piece of flip chart paper and ask them to spend 20 minute listing how events and meetings can be more inclusive.

Black/Minority Ethnic Communities
People with Disabilities
People with Learning Disabilities
People with Visual Impairments
People with Hearing Impairments
People with Dementia
Children and Young People

Ask each group to feedback

Give participants handouts on ‘Engaging Diverse Groups and Communities’
A person’s sense of ‘self’ may be influenced by one or more factors such as their race, gender, age or sexuality. People may also feel they share similar life experiences with others. There are also the ‘hidden’ or vulnerable groups to consider such as asylum seekers, travellers, people living in private sector care homes or people living in poverty.

Inclusion is the right of everyone with personal experience of mental distress regardless of diagnosis or length of experience. This also includes people who do not ‘use’ services because they have recovered, choose not to or are not eligible.

(cited NIMHE 2006 Making a Real Difference Work Group 4 Minimum Standards For Working with Diverse Groups and Communities)

A set of minimum standards has been developed with a set of overarching principles which state they will:

✓ Apply to all programme and activities at national or regional level
✓ Acknowledge the rights of all service users and carers to work with the organisation whatever their background
✓ Be part of a culture change within the organisation towards a more people-focused approach built on mutual respect
✓ Require commitment and resources from all levels within the organisation

This is not about:

✗ Putting people into boxes and treating them accordingly
✗ Saying any one group or community is more important than another
✗ Having a ‘tick box’ or ‘politically correct’ attitude to involvement
✗ Setting up complicated systems of representation or prescribing how to engage with people

The important points from NIMHE are:

1. Take a positive attitude to diversity, which celebrates different cultures and respects every person as an individual
2. Address the structural barriers to involvement faced by different groups and communities including the impact of discrimination
3. Provide practical and personal support to enable the participation of users and carers from a wider range of backgrounds
4. Make information more accessible to the individuals, groups and communities with whom they are working
5. Make events and activities inclusive of the individuals, groups and communities with whom they working

6. Develop more flexible and creative ways of engaging different groups and communities

7. Show commitment as an organisation to mainstreaming equality and diversity of service user and carer involvement in its corporate policies, procedures and workforce

8. Build upon existing networks, resources and positive practice

9. Develop mutually supportive relationships with local communities and stakeholder groups

10. Ensure systems of service user and carer involvement support the needs of diverse groups and communities
Overarching Principles

✓ Apply to all programme and activities at national or regional level

✓ Acknowledge the rights of all service users and carers to work with the organisation, whatever their background

✓ Be part of a culture change within the organisation towards a more people-focused approach, built on mutual respect

✓ Require commitment and resources from all levels within the organisation

(CSIP 2007)
Overarching principles

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- Make events and activities inclusive of the individuals, groups and communities with whom they are working.

(CSIP 2006)
- Develop more flexible and creative ways of engaging different groups and communities

- Show commitment as an organisation to mainstreaming equality and diversity of service user and carer involvement in its corporate policies, procedures and workforce

- Build upon existing networks, resources and positive practice

- Develop mutually supportive relationships with local communities and stakeholder groups

- Ensure systems of service user and carer involvement support the needs of diverse groups and communities

(CSIP 2007)
Exercise: Thinking Creatively

**Brief description**

A small group exercise to consider and develop ideas of how to break out of ‘traditional’ ways of thinking and to be more creative.

**Objectives**

The purpose of this exercise is:
- To enable participants to begin to think in a more creative style
- To help participants broaden their views and ideas
- To explore the idea of doing things differently
- To consider the impact this may have on service users and carers

**Preparation**

Photocopy handout ‘Thinking Creatively’

**Resources**

Paper and pens
Handout of ‘Thinking Creatively’
Time needed 30 – 45 mins

**How to run it**

Explain to participants that this exercise is to explore the need to move away from doing everything the same to doing things differently. Suggest that often we fall into habits and do not question why we are doing things. Sometimes just by doing things differently in small ways can make a difference to a service user or carer.

Split participants into small groups of 3 – 6 depending on group numbers. Allocate each group to look at one of the examples in the handout and ask them to consider what rules or norms govern this. For example ‘Access to services’ rules might include a GP referral letter, appointments in clinics or a letter to the service user with an appointment made.

Give participants around 5 – 10 mins to think of ideas.

Now state to the group that they must pick one or two rules that they have identified. Now tell them that from Monday the government has now made those rules illegal.

Explain to the groups that they must think of different ways to manage this and to consider the impact of these changes.

After around 10 mins bring back everyone into a whole group and feedback and have a group discussion.
Handout: Thinking Creatively

1. Consulting service users and carers on a change in day services.

2. Holding a conference on “Recovery”

3. Asking service users and carers to sit on a Clinical Governance Committee

4. Having an appointment with a GP

5. Training student nurses

6. Having to visit a psychiatrist in a crisis

7. Being asked to involve service users and carers in a project
### Exercise: Finding creative new solutions

**Brief Description**

A group exercise to re-define a problem and find possible solutions to it through the use of metaphor and using a creative process.

**Objectives**

The purpose of the exercise is:

- Through use of metaphor view a problem from new perspectives
- Generate helpful associations to the difficulty
- Indicate possible new approaches to a solution

**Preparation**

None

**Resources needed**

Time needed – 20 – 30 mins

**How to run it**

Either remain as a whole group or break into smaller groups. Specify a problem or get the group to specify a problem of its own choosing.

Ask the group to generate a number of metaphors or analogies for the problem. For example it might be observed that efforts to achieve planned change often fail and that change often seems to arise spontaneously in unplanned ways in small pockets. A metaphor for this might be that change where it occurs is like ‘Flowers in the Desert’.

Next ask the group to construct a set of justifications as to why the metaphor is valid. In the above example one justification might be to see unplanned changes as windblown seeds alighting in conditions suitable for growth.

The group then uses the justifications to generate associations. An association in our example might be that the seeds are individuals with a common idea, who may or may not find themselves in circumstances where they may develop the idea.

The final part of the exercise is to use the new insights to generate ideas for practical solutions.

Finally conduct an open discussion to feedback the experience of creating and using metaphors.
Exercise: Payment and Reimbursement

**Brief Description**
An exercise to explore the issues surrounding payments and reimbursement to people in receipt of state benefits

**Objectives**
The purpose of this exercise is:
- To consider the issues and implications surrounding reimbursement for involvement
- To explore a range of ways of appreciating service users and carers involvement
- To receive and read a copy of ‘Valuing Involvement – Payment and Reimbursement Guidance’.

**Preparation**
Photocopy handout ‘Benefits and Involvement’ by Peter Beresford.
Write questions on flip chart

**Resources needed**
‘Valuing Involvement – Payment and Reimbursement Guidance’ (NIMHE 2006) and ‘Reward and Recognition’ (DH 2006) for each participant
Handout ‘Benefits and Involvement’ – Peter Beresford
Flip chart and pen
Flip chart paper
Time needed – 45 mins

**How to run it**
Put participants into small groups of 3-4.

Explain that this exercise is to consider the implications for service users and carers around receipt of reimbursement particularly if they are in receipt of certain benefits.

Ask them to read the handout ‘Benefits and Involvement’ by Peter Beresford and consider the questions on the flip chart.
1. What are the difficulties for people who wish to be involved and are receiving benefits?
2. What can be done to help these issues?
3. What would you do when asking people to be involved?
4. What other ways can people feel appreciated?

Inform the groups they have 30 minutes to answer the questions onto flip chart paper.

After 30 minutes hold a whole group discussion with feedback.

Give all participants a copy of ‘Valuing Involvement – Payment and Reimbursement Guidance (NIMHE 2006) and ‘Reward and Recognition’ (DH 2006)
Benefit claimants are caught in a catch-22 over civic involvement, says Peter Beresford

Wednesday October 19, 2005
The Guardian

A key plank of the government's policy is putting the public and patients at the centre of health and welfare. All the talk is of partnership and user involvement; the "expert patient" and the "active citizen". Yet evidence shows that the government's own benefits policy is pushing people in the opposite direction, discouraging them from making a contribution and perpetuating their social exclusion.

This is the finding from a Department of Health-funded national study published today - Contributing On Equal Terms: Service Users Involvement and the Benefits System - and carried out by Shaping Our Lives, an independent service user organisation.

The government wants user involvement: in professional training and education, research, audit, regeneration, and the planning and administration of trusts and hospitals. But many service users who are on benefits say that if they go to the meetings, get involved in the groups, or act as volunteers, their benefits can be at risk.

"They force you back into work when you're not ready. They think that, if you are fit enough to go to these meetings, you're fit enough to go to work," says one service user who was interviewed.

A culture of fear has developed, say others in their responses: "People have terrible anxieties about these issues," and "You walk down the street with all the posters up about fraud and the adverts on TV. It all feeds into your head ... you're already suffering from anxiety and depression. It's just going to make you worse." As a result, many people on low income, disabled people and mental health service users are discouraged from getting involved.

However, the study shows that the skills, confidence and self-esteem that service users gain from such involvement are frequently transferable and can make a real difference in enabling them to rejoin the labour market.

But rules relating to benefits are not always clear and often are not implemented accurately or consistently. Service users can find it very difficult to talk to Jobcentre Plus and it can take a long time to sort things out when benefits are wrongly withdrawn. Some found staff at Jobcentre Plus unhelpful and unfriendly. They say: "Jobcentre Plus has no understanding of the recovery process," and "You're trapped if you work and you're trapped if you don't."
One of the strongest messages from the study is the real commitment of many people who have been written off as "dependent" to make a contribution to their community. But this is hindered by official talk of "benefit cheats"; of getting "a million people off incapacity benefit"; a preoccupation with paid employment; and an often inflexible and unsupportive labour market.

However, some positive developments are taking place. A new phone support line is being planned and new guidance on payment is in the pipeline. But service users feel that more fundamental change is needed in the benefits system if it is to develop trust and ensure that being an active citizen and patient does not result in benefits being withdrawn.

Levels of permitted earnings need to be reviewed and consistently applied. But service users’ fear is that any change in legislation or guidance that this might require could be rejected by the Treasury on the grounds of opening the floodgates of benefits expenditure, when, in fact, it might represent a way of setting realistic limits to it.

Contributing on Equal Terms, by Michael Turner and Peter Beresford, is available from the Social Care Institute for Excellence. Peter Beresford is professor of social policy at Brunel University.
**Exercise:** The impact of using jargon

**Brief description**
Through an individual, experiential exercise this is designed to make participants much more aware of their use of language and to consider how use of jargon can affect service users and carers.

**Objectives**
The purpose of this exercise is:
- To reflect on appropriate use of language and avoid jargon
- To consider the way jargon can exclude service users and carers
- To consider the implications of not understanding information.

**Preparation**
Exercise 1. If possible tape the Shipping Forecast from the Met Office
Exercise 2. Photocopy questionnaire 'Acronyms' and answer sheet

**Resources**
Exercise 1 - either a tape of the 'shipping forecast' or read out the resource sheet 'Shipping Forecast' trying to replicate how they speak.
Flipchart & pen
Exercise 2 – questionnaire ‘Acronyms’ & answer sheet
Time needed - 30 mins

**How to run it**

**Exercise 1**

Without introducing the exercise just ask people to listen carefully as they will be asked questions on it afterwards.

Preferably play a tape of the ‘Shipping Forecast’ or read out from the handout.

Ask participants that if they were about to take a boat out with people on board whom they are responsible for how does it feel to not understand (ask the ‘sailors’ to be silent!) and what are the implications of this?

Suggest unless they are sailors they would have no reason or knowledge in the shipping forecast. Ask the participants to consider how it feels if you are a service user or carer who also often has little knowledge of jargon and acronyms. Have a brainstorm onto a flipchart of the impact of using jargon. Discuss as a whole group.
Exercise: The Impact of using jargon

Exercise 2 (Continued)

Give participants the ‘Acronym’ questionniare. Ask participants to work in pairs and fill in what you think correct answer is from acronyms. Tell them they have 15 mins. Then give them answers.

Ask the participants to consider how it feels if you are a service user or carer who also often has little knowledge of jargon and acronyms. Have a brainstorm onto a flipchart of the impact using jargon. Discuss as a group.
THE GENERAL SYNOPSIS AT 0700
HIGH EAST FITZROY 1023 EXPECTED SWITZERLAND 1026 BY 0700 TOMORROW

VIKING NORTH UTSIRE SOUTH UTSIRE FORTIES
NORTHWEST 5 TO 7, BUT 4 AT FIRST IN NORTH UTSIRE, BACKING SOUTH 4 OR 5. RAIN OR SHOWERS. MODERATE OR GOOD

CROMARTY FORTH TYNE DOGGER
NORTHWEST BACKING SOUTH OR SOUTHWEST 4 OR 5, DECREASING 3 FOR A TIME.
RAIN LATER. MODERATE OR GOOD

FISHER GERMAN BIGHT
NORTHWEST BACKING SOUTHWEST 4 OR 5, OCCASIONALLY 6 AT FIRST. SHOWERS DYING OUT. MAINLY GOOD

NORTH FITZROY SOLE
SOUTHWEST 4 OR 5, INCREASING 6 FOR A TIME. OCCASIONAL RAIN.
MODERATE OR GOOD

ROCKALL
SOUTHEAST 5 TO 7 VEERING SOUTHWEST 4 OR 5, OCCASIONALLY 6 LATER. RAIN, THEN SHOWERS. MODERATE BECOMING GOOD

FAIR ISLE FAEROES SOUTHEAST ICELAND
NORTHWEST 5 OR 6 BECOMING VARIABLE 3 OR 4 THEN EAST OR SOUTHEAST 4 OR 5, OCCASIONALLY 6 LATER IN SOUTHEAST ICELAND.
RAIN AT TIMES. MODERATE OR GOOD

(Met Office Sept 2006)
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<thead>
<tr>
<th></th>
<th>Acronyms – questionnaire</th>
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<tbody>
<tr>
<td>1.</td>
<td>ABCD</td>
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<td>2.</td>
<td>AFOL</td>
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<td>AFTO</td>
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<td>4.</td>
<td>BEER</td>
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<td>5.</td>
<td>BOBFOC</td>
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<td>6.</td>
<td>CRAFT</td>
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<td>7.</td>
<td>FEAR</td>
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<td>FINE</td>
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<td>SWALK</td>
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<td>14.</td>
<td>T-CUP</td>
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1. **ABCD**

**Above and Beyond the Call of Duty.** Whether this acronym originated in the armed services is not clear. These days it is just as applicable to the civilian work environment, and particularly the need to ensure a healthy work-life-balance. A reminder also for all managers and corporations that people who go the extra mile, beyond normal expectations, are to be treasured and suitably rewarded, not exploited. (ack T Rowe)

2. **AFOL**

All Fine On Leaving.

3. **AFTO**

Ask For The Order. The 'psychological imperative' and one of the most important rules of selling, despite which, millions of sales people usually forget it.

4. **BEER**

**Behaviour, Effect, Expectation, Results.** The headings by which to assess performance of anything, particularly a new initiative. A great discipline when working with a team or delegating another to conduct a review, when it's important to keep the review focused.

5. **BOBFOC**

Body Off Baywatch, Face Off Crimewatch. Nightclub and dating vernacular, and not gender specific.

6. **CRAFT**

**Can't Remember A Flipping Thing.** This acronym has various uses: for example Monday morning after Glastonbury or the Prague stag/hen weekend; those 'Senior' moments experienced by folk of advancing years. Or a tedious training course or meeting, or one of those awful 'pep up the workers' roadshow presentations by the new board of directors.

7. **FEAR**

**Forget Everything and Run.** One of the best reverse acronyms ever devised (bacronym is the modern term). (Ack A Davice) It's what happens when the fear response takes over, and the primitive brain switches to auto-pilot. Great for presentations training and 'training the trainer', to emphasise why nobody ever does anything really well under extreme stress except shut down.
8. **FINE**

Fanatical, Insecure, Neurotic and Emotional. Alternative ironic acronym response to the universal question, 'How are you?.....' (Ack D Jenkins). An alternative meaning: **Feelings Inside Not Expressed**, notably in the context of attitude, communications, coaching, life-change, etc. People commonly respond to the question, "How are you?" by saying "Fine," when they perhaps are anything but fine. (Ack K Freeman)

9. **KISS**

Keep It Simple Stupid. One of the all time great acronyms, and so true. A motto and reminder that simplicity works - in communications, design, philosophy, relationships, decision-making, meetings, management and life generally. Apply and promote KISS to any situation to deter unnecessary complication, excuses, bureaucracy, red-tape, and to encourage practical positive outcomes, no-nonsense communications, integrity, truth, beauty, and honesty.

10. **LBIAC**

Left Brains In Airport Carpark. As used by airport and airline ground handling staff the world over, and also very good for inattentive delegates who've had to make an expensive air trip just to fall asleep on your training course. (Ack. David Rawsthorn)

11. **NKDA**

No Known Drug Allergies. Alternatively the abbreviation is used to mean Not Known, Didn't Ask.

12. **PITSA**

Person (or Passenger) Intoxicated Through Substance Abuse. Allegedly a London Underground tube system acronym used by certain staff to describe a member of the public found un-conscious or semi-conscious on station premises. The product of the victim's over-indulgence when present on the platform is known colloquially as a 'Platform Pizza', leading to occasional word play with the similarity in the sounds. (Ack A Butler)

13. **SWALK**

Sealed With A Loving Kiss. A kind of wartime envelope text message to a loved one

14. **T-CUP**

Total Control Under Pressure. Used to emphasise the need for concentration and focus, by the England rugby coaching staff.
**Brief description**
A small group exercise that will enable participants to consider how mental health service users and carers may think, feel and behave and the difficulties this may place on them when becoming involved.

**Objectives**
The purpose of this exercise is:
- To enable participants to gain an insight of how it might feel to experience mental distress
- To consider the effect of mental distress on families, friends and carers
- To appreciate the impact this may have when people become involved with a mental health organisation

**Preparation**
Prepare handout

**Resources**
Flip chart paper
2 handouts:
- ‘Being with someone who is showing emotional distress’
- ‘Mental illness as an exaggeration of feelings’

Time needed – around 30 – 40 mins

**How to run it**
Explain that the exercise is to gain understanding on how mental illness may affect both people who are experiencing mental distress and their carers. Also to understand this may impact on any participation with an organisation.

Put participants into small groups of 4 – 5. Give each group some flipchart paper and ask the group to appoint a scribe.

Ask the participants to spend a few minutes silently thinking of a person known to them who has experienced mental distress. This person may be themselves, a relative, friend, neighbour or acquaintance.
**Exercise:** Gaining Insight

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**How to run it (continued)**

In the group spend 10 minutes making a list of words that describe what the person was thinking, feeling or doing when they were experiencing mental and emotional distress.

Similarly spend 10 mins making a list of words that describe how the carers of this person may be thinking, feeling or doing.

Feedback as a whole group discussion.

Spend 15 mins as a whole group discussing how these issues of thinking, feeling and doing may impact when people become involved with a mental health organisation. Consider if anything can be done to help the issues that arise.
Handout: Being with someone experiencing emotional distress

In the course of your work you may find that the person you are working with is showing signs of emotional distress. There are a variety of things that you can do to help the person as your support and encouragement can be extremely important. Whilst the majority of people suffering mental distress do not present a risk you must have an awareness for your own safety.

These are a few suggestions:

- Be open to listening to the person even if what they are saying does not make sense.
- Stay calm if the person is agitated, upset, or talking about harming themselves.
- Do not challenge their views or get into a confrontation about what they perceive as reality.
- Reassure the person – you are there to help – accept how they see things, acknowledge their distress
- Ask them what has helped them in the past if they have felt like this
- Offer empathy, listen and offer to contact someone if they wish, for example, their carer, friend, GP or Care Co-ordinator.
- If you need more help or support talk to your line manager
Handout: Mental illness is an exaggeration of feelings we all have

It is important for us to recognise that mental illness is an exaggeration of feelings we all have and not a different kind of feeling or experience. By recognising this statement as true it can enable us to understand what may be happening for a person who experiences mental illness.

At times we all may:

- Have imaginary fears – we might imagine that the creaking boards late at night means an intruder is in the house. Walking late at night in the dark may lead us to imagine we are being followed.

- Daydream about imaginary situations we would like to happen

- Have conversations with ourselves (maybe in our heads) to rehearse something or work out what to say in an argument.

- Become so angry or upset we are frightened about what we might do

- Want to shut ourselves away from everyone for a few hours privacy when we don’t feel like talking to anyone

- Think someone has it in for us or doesn’t like us.

- Feel nothing good is happening, that everything is going wrong and we can’t find the energy or will to sort it out

- Have nightmares which leave us feeling disturbed and distressed the next day

- Carry out rituals that are important to our feeling of well being.

When these normal fears and experiences become so great that they affect our lives, and stop us from working or living our lives as we usually do, we may be considered mentally unwell.
Session  Achieving and measuring outcomes

**Brief Description**
An exercise that enables participants to consider that obstacles need to be recognised, worked upon or removed to achieve desired outcomes and to consider why and how to measure outcomes

**Objectives**
The purpose of this exercise is:
- To identify obstacles
- To convert obstacles into ‘How to’ statements
- To consider why and how to measure the outcome
- To appreciate the whole process of achieving change

**Preparation**
Photocopy handout
Write headings on flip charts

**Resources needed**
‘Examples of desired outcomes’ handout
4 flip chart sheets and stands or blue tack
2 different coloured marker pens
Time needed – 30 to 40 mins

**How to run it**
Line up four flip chart stands or stick four sheets of flip chart paper to the wall. Write the following starting with the far left sheet
1. Where we are now?
2. What are the obstacles?
3. Where we would like to be?
4. How do we know we have achieved this?

Give the group the handout of examples of outcomes and ask them to identify a desired outcome either from the sheet or generate their own example to work on.

Write this outcome on the third flipchart – with heading ‘where we would like to be’. Next, on the left hand flipchart ‘Where we are now?’ brainstorm with the group the principle features of the current state.

Now on the next flipchart ‘What are the obstacles?’ ask the group to brainstorm the obstacles of getting from sheet one to sheet three. Some of these obstacles may well be in the ‘Where we are now’ statements on sheet one but also include these with other obstacles on the middle flipchart.

Then, rephrase the obstacles as ‘How to’ statements using a different coloured marker. Have a discussion on what change this could bring about.
### Session

<table>
<thead>
<tr>
<th>Achieving and measuring outcomes</th>
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</table>

**How to run it (continued)**

Remind the group that a solution is not a solution until you can recognise and find a way around or remove any obstacles.

Then look at the final flip chart sheet ‘How do we know we have achieved this?’ and brainstorm different ways that the outcomes can be measured with both qualitative and quantitative methods.

For example: holding a focus group, having a questionnaire with open ended questions or a tick box exercise.

Suggest to group it is essential to continually monitor and evaluate what work is being done, reflect on and learn from both mistakes and successes. With any form of evaluation it is essential to involve service users and carers and if possible enable them to do the monitoring and evaluation.

It is also important to continually monitor and evaluate how service users and carers are actually being involved in order to ensure continual high quality involvement.
- Change professional practice through service user and carer involvement in education
- Ensure changes are clearly linked to service user and carer participation
- Create employment opportunities for service users and carers
- Increase capacity within service user and carer groups
- Involve children and young people in change and service development
- Put in place good feedback mechanisms
- Create stronger links with service user and carer groups
- Have more diverse voices involved
- Change services on offer to people with dementia
- Have more BME involvement in service development and change
- Develop opportunities to involve people in secure settings within decision making
### Exercise: Taking effective involvement forward

**Brief Description**  
A brief exercise to enable participants to reflect on their own practice or that of the organisation and to consider areas for change.

### Objectives

The purpose of this exercise is
- To enable reflection on current practices as individuals or as an organisation
- To complete a SWOT analysis looking at strengths, weaknesses, opportunities and threats
- To reflect on course ‘learning on effective involvement’ and consider its application within the workplace.

### Preparation

Photocopy handout

### Resources needed

- SWOT analysis handout
- Time needed - 30 minutes

### How to run it

This exercise is to be run at the end of the course and to enable participants to reflect on their learning of effective involvement of service users and carers.

Ask people to decide if they would like to work on individual practice or on organisational practice. If working on the organisation it may be more appropriate for people to work in small groups otherwise ask them to work individually.

Give everyone a SWOT analysis handout and ask them to complete it reflecting either on their own work around involving service users and carers or that of the organisation.

Remember: **strengths** and **weakness** are **internal** and there is **direct control**, however **threats** and **opportunities** are generally **external**.

Give people 20 mins.

Have whole group discussion on findings and ask people to share any next steps they wish to put into practice. Taking the weakness and threats and changing them into strengths and opportunities.
<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunities</td>
<td>Threats</td>
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</tbody>
</table>
References


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Care Services Improvement Partnership (CSIP) /National Institute Mental Health England (2006) Good Practice Guidance for Involving Mental Health Service Users and Carers


Care Services Improvement Partnership. (2006) Service Improvement Guide. CSIP

Care Services Improvement Partnership(CSIP) /National Institute for Mental Health England (2006) Minimum Standards for working with Diverse Groups and Communities. CSIP


HASCAS (2005) Making a Real Difference, Strengthening Service User and Carer Involvement in NIMHE. York: NIMHE North East, Yorkshire and Humber


Race Phil [www.phil-race.com](http://www.phil-race.com)


Wallcroft J, Read J, Sweeney (2003) *On Our Own Terms. Users and survivors of mental health services working together for support and change* London; The Sainsbury Centre for Mental Health

Other resources

Black and ethnic minority

Begum N (2006) *Doing it for themselves: participation and black and minority ethnic service users*. Bristol; Social Care Institute for Excellence & Race Equality Unit
www.scie.org.uk and www.reu.org.uk


Carers


From Carers UK website www.carersuk.org

Children and Young People

www.nya.org.uk/hearbyright


Street C, Herts B (2005) *Putting Participation into Practice- A guide for practitioners working in services to promote mental health and wellbeing of children and young people*. Young Minds
Dementia


A series of ‘Hearing the Voice of People with Dementia’ materials has been published by Dementia Services Development Centre. Website [www.dsdc.stir.ac.uk](http://www.dsdc.stir.ac.uk)

Involvement / Participation


HASCAS (2005) *Making a Real Difference, Strengthening Service User and Carer Involvement in NIMHE*


Social Care Institute for Excellence (2004) Has service user participation made a difference to social care services? London: SCIE


Learning Disabilities

Valuing People www.valuingpeople.gov.uk


Standing Conference of Voluntary Organisations for People with a Learning Disability in Wales SCOVA (2000) Too Many Pages – Guide to Involving service users to make services better. Cardiff: SCOVA E mail cardiff2@scova.demon.co.uk

Mental Health


Newnes C, Holmes G, Dunn C (1999) This is Madness; A critical look at psychiatry and the future of Mental Health Services. Ross-on-Wye; PCCS Books


Wallcroft J, Read J, Sweeney (2003) On Our Own Terms. Users and survivors of mental health services working together for support and change London; The Sainsbury Centre for Mental Health
Older People

Better Government for Older People website www.lbhf.gov.uk


## Glossary

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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td>Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.</td>
</tr>
<tr>
<td>Care Services Improvement Partnership (CSIP)</td>
<td>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.</td>
</tr>
<tr>
<td>Experts by Experience (EbE)</td>
<td>A national service user and carer group which was part of NIMHE.</td>
</tr>
<tr>
<td>Local Implementation Team (LIT)</td>
<td>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.</td>
</tr>
<tr>
<td>National Institute for Mental Health England (NIMHE)</td>
<td>Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.</td>
</tr>
<tr>
<td>PCT (Primary Care Trust)</td>
<td>Organisations which are based in primary care and responsible for commissioning health services for the local population.</td>
</tr>
<tr>
<td>Programme Lead</td>
<td>A member of NIMHE staff responsible for leading a programme of NIMHE’s work either at a national or a regional level.</td>
</tr>
<tr>
<td>Regional Development Centre (RDC)</td>
<td>NIMHE has eight regional development centres.</td>
</tr>
<tr>
<td>Service user</td>
<td>Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems.</td>
</tr>
</tbody>
</table>
Other Terms used within this report include;

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

RATIFYING BODY …………………………………………………………………………………

DATE RATIFIED …………………………………………………………………………………

NEXT REVIEW DATE ………………………………………………………………………………

TO BE APPROVED BY ………………………………………………………………………………

Resource Pack for Trainers and Facilitators
2007