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Partners:

• NSUN: the National Survivor User Network
• Afiya Trust
• Social Perspectives Network
• Mental Health Foundation
Our Vision

Our vision is of a future where there is ‘nothing about us without us’:

• where effective and meaningful involvement in all aspects of our lives builds resilience and changes people’s lives;
• where there is genuine partnership working between mental health services, professionals, service users and carers, based on agreed and shared outcomes; and
• where this partnership of expertise works towards common goals of respect, recovery, choice and control for each and every individual who comes to use mental health services.
Historical References, Resources and Experiences

• Previous work for Dept of Health, NIMHE, CSIP, NMHDU
• Two Literature reviews: of involvement and of involvement tools and guidelines
• Reports:
  – ‘On Our Own Terms’ – Jan Wallcraft and others, 2003
  – ‘Unlocking Service User Involvement in Forensic Settings’ – WISH 2011
• Consultations (by NSUN in 2012/13)
• Pilot site events and Leadership programmes
Principles:
- Meaningful and inclusive involvement starts with a commitment to shared principles and values; start by sharing your principles and values.

Purpose:
- The purpose of involvement needs to be clearly stated and communicated with everyone involved.

Presence:
- A diversity of service users and carers should be involved at all levels and at all stages; the people who are involved need to reflect the nature and purpose of the involvement.

Process:
- The involvement process needs to be carefully planned to make sure that service users and carers can make the best possible contribution

Impact
- Any involvement needs to make a difference to the lives or the experiences of service users and carers.
- We recommend a cycle of learning and development
Principles 1

A commitment:

• to improve services and to improve the mental health, wellbeing and recovery of all individuals;
• to acknowledge the power differentials that exist between people, and a commitment to minimise them wherever possible;
• to listen to service users and carers with respect and openness;
• to change in response to the views of service users and carers;
• to support race equality and to challenge discriminatory practices;
• to an open-minded approach towards cultural differences and ‘re-imagining’ ways of working.
Principles 2

Principles of:

- Inclusivity, equality of opportunity and fairness;
- Clarity and transparency;
- Flexibility
- Sensitivity about language and actions... an understanding that there are different ways of expressing and doing things
Purpose

- The purpose of involvement is clearly stated, agreed and communicated with everyone involved;
- Clarity about individual roles and involvement activities for service users and carers;
- Clarity & transparency about the potential for change and the limits to change;
- The intended outcomes for involvement are agreed and recorded at the start in order that they can be monitored and evaluated.
Presence 1

- Service users and carers involved at all levels and stages of an activity, organisation or project;
- A diversity of service users and carers involved;
- Service users and carers offered the option to be involved separately as their views and priorities may be different;
- A minimum of two and ideally three service users/carers in any meeting, with a reserve person at high level meetings.
• Analyse the relevant population
  – to ensure that the involvement activity can reflect that population;
  – and to ensure that people particularly affected by the service or issues under consideration are actively approached for inclusion.

• Establish monitoring procedures from the start;

• Potential roles for service users and carers:
  ✓ Ambassador
  ✓ ‘Critical friend’
  ✓ Co-worker
  ✓ Consultant
  ✓ Expert by experience
Process

Engagement
– Information made widely available
– A range of ways of getting involved
– A fair and transparent recruitment process
– Role descriptions
– Accessible and inclusive approaches

Communication
– Clear and regular communications, jargon-free
– Timing
– Feedback
– Decision-making processes clear and transparent

Support and Training
– Practical, supervisory and emotional support
– Training shared to enable all to work together well

Practical Issues
– Budget, travel, expenses for support needs
Impact 1: Questions

1. What were the intended outcomes of the involvement activity?
2. What difference(s) have service users and carers made to the project, activity or organisation?
3. How did everyone feel about the process of involvement?
4. Did the involvement of service users and carers make a difference to the end result of the activity/project?
5. Did the involvement of service users and carers make a difference beyond the activity itself – to the delivery of services or the understanding of mental health, to the recovery or wellbeing of individuals?
Impact 2: Themes

Impact needs to be explored in the following areas:

• Ethos/culture
• Policy and Planning
• Delivery
• Outcomes and outputs
• Diversity and equality of opportunity
• The service user and carer experience of the service
A Cycle of Learning and Influence

1. Find out
2. Make a plan
3. Make things happen
4. Watch and listen
5. Think and discuss
6. Change your plan

4pi National Involvement Standards
Principles Purpose Presence Process Impact
Overarching themes

• Power
• Diversity and equality
• Principles and values
• Commitment to change
• Barriers and challenges
Next Steps...What does implementation look like?

• Sign-up
• Online resources
• Self-evaluation tool
• An implementation guide, route-map or pathway?