
Executive Summary



**‘Nothing about us
without us’**

4pi National Involvement Standards



Principles

Purpose

Presence

Process

Impact

The National Involvement Partnership (NIP) project is led by National Survivor User Network (NSUN) and includes the following organisations: Afiya Trust, Social Perspectives Network (SPN) and the Mental Health Foundation. This three year programme of work is funded by the Department of Health, and aims to bring together all of the knowledge and expertise about service user and carer involvement, built up over the last few decades, in one place.

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4pi National Involvement Standards



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Introduction

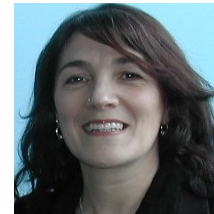
The 4Pi National Involvement Standards have been developed by the National Involvement Partnership (NIP) project, a partnership of organisations hosted by the National Survivor User Network (NSUN). The idea behind the project is to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and social care services. The project aims to share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates the involvement of service users and carers throughout and beyond services.

The 4Pi framework has been developed by mental health service users and carers. The involvement of people with lived experience of mental distress and their carers and family members has formed the basis of the work. However the framework has universal relevance: it is simply a means to enable services, organisations and individuals to think about how to make involvement work well.

This is a summary of the main report. The full report 'Involvement for Influence: the 4Pi Standards for Involvement' (NSUN, 2014) is available from the NSUN website: www.nsun.org.uk



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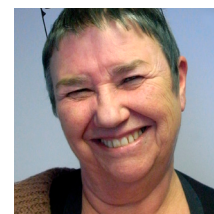
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Thanks also to the members of the National Involvement Partnership Advisory Group and everyone who participated in the consultations over three years.

Remembering Denise Forde who sadly passed away in 2014.



Above: The NSUN Team and Trustee Development Day 2014. Visioning for the future.

A note on language

For the purposes of this project and the 4Pi standards, we have continued to use the term 'involvement'. However, we are aware that different words are used by different organisations at different times; these include: consultation, participation, engagement, co-production. Some terms imply a greater level of influence or power; however, sometimes the language does not reflect the underlying ethos or purpose. Our concern throughout is with meaningful involvement – involvement with influence – and with genuine partnership working.

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 experiencing mental distress.

Why involvement?

The evidence tells us that good involvement can transform people's lives, improve services and develop the resilience of communities.

- Involvement in individual care and treatment can increase self-esteem, improve individual outcomes and increase people's satisfaction with services. The greatest benefits result when people agree with the purpose of their treatment, and when they have choice and control over it.
- Involvement in communities can build resilience, provide opportunities for peer support and mentoring and increase our social capital¹.
- Involvement in services can lead to enhanced quality of care, improved quality of life, a reduction in compulsory admissions, improved relationships between staff and service users, and improved outcomes for service users; it can also lead to improved outcomes for providers.
- Involvement in planning, commissioning and governance can improve information and access for service users, and have positive effects on decision-making processes and staff attitudes and behaviour. It is vital that service users are involved in defining the outcomes of services for these benefits to be maximised.

1. Social capital has been described as the glue that holds communities together: it is a property of groups rather than of individuals and is thought to be a mediating factor between a community, the collective attributes of its members and individual health.

The 4Pi National Involvement Standards

Our work has led to the development of the 4Pi framework for involvement: a simple, yet robust framework around which to base standards for good practice, and to measure, monitor and evaluate involvement. The framework builds on the work of many people: service users and carers and others who have lived and breathed involvement and shared their experiences in various ways, both written and unwritten. We do not suggest that every element in this framework needs to be in place before any involvement takes place. But we do suggest that these are all important things to think about if you are looking to develop meaningful and effective involvement.

PRINCIPLES

'The key point is respect and equality in working relationships... the service user is on the same level as staff, otherwise (involvement) doesn't work'
Participant in NIP Consultations

Meaningful and inclusive involvement starts with a commitment to shared principles and values. Our work suggests that involvement benefits from the following shared principles and values:

**'The key point is respect
and equality in
working relationships...'**

A commitment to:

- improve services and to improve the mental health, wellbeing and recovery of all individuals;
- acknowledge the power differentials that exist between people, and a commitment to minimise them wherever possible;
- listen to service users and carers with respect and openness;
- change in response to the views of service users and carers;
- support race equality and to challenge discriminatory practices;
- an open-minded approach towards cultural differences and diversity in ways of working;
- inclusivity, equality of opportunity and fairness;
- clarity and transparency;
- sensitivity about language and actions... an understanding that there are different ways of expressing and doing things.

PURPOSE

'So it is important to clarify the purpose of involvement, how much influence a person has in the process, and how much capacity and will there is within the organisation to bring about change as a result of the involvement.'

(quoted in Kalathil, 2008/2011)

Meaningful involvement needs to have a clear purpose against which it can be monitored.

- The core purpose of any involvement activity should be to improve services and the experience of services for service users and carers;
- The purpose of involvement needs to be both clear and shared with all of the people who are likely to be affected by the involvement activity;
- The purpose of individual roles and involvement activities needs to be clear;
- The potential for change and the limits of change need to be made clear;

‘So it is important to clarify the purpose of involvement, how much influence a person has in the process...’

- The goals or expected outcomes should be agreed and recorded at the start in order that they can be monitored and evaluated.

PRESENCE

‘I think they ought to be involved at the highest level. I don’t know if service users and carers are being encouraged to get involved at board level. But that’s what I’d like to see... We can all be involved at all levels and that would really make it work, I think.’
Service user

- Service users and carers should be involved at all levels within the organisation, project or activity including at decision-making levels²;
- Service users and carers involved in an activity should include people from diverse backgrounds and communities. This is particularly significant for communities who are over-represented within mental health services as a whole.
- The population relevant to the involvement should be analysed at the start, in order to ensure that those involved reflect that population, and to identify which groups of people are particularly affected by the service or issues under consideration and who therefore need to be involved.
- Monitoring procedures need to be in place to monitor the presence of service users and carers,

and the diversity of those involved, throughout these levels.

- These are some potential roles for service users and carers involved in organisations (this is not an exhaustive list; other roles are also possible):
 - Ambassador (i.e. committed to the ethos of the work stream or programme, promoting it, spreading the word, engaging others)
 - ‘Critical friend’ (i.e. both programme and involved users/carers able and prepared to engage in meaningful debate to reach a satisfactory negotiation of work programme/policy/delivery)
 - Co-worker (i.e. working directly with programme members to deliver the work of the programme)
 - Consultant
- Care should be taken to ensure that service users and carers can be involved separately or give their views in separate ways as their views and priorities are likely to be different.
- There should be a minimum of two and ideally three service users or carers in any meeting, with a reserve person at high level meetings; one service user or carer should never be expected to attend a meeting and represent the views of service users or carers.

‘I think they ought to be involved at the highest level...’

2. There is a potential contradiction between this and Purpose; if it is agreed that there is no clear purpose for involvement at a particular level then involvement might be at risk of being tokenistic.

PROCESS

'I think they ought to be involved at the highest level. I don't know if service users and carers are being encouraged to get involved at board level. We need to be involved at the very beginning, with the development of the service rather than just delivery' - Participant in NIP Consultations

The involvement process needs to be carefully planned and thought through, in order to ensure that service users and carers (and everyone) can make the best possible contributions. We have grouped the issues covered by Process under the following headings: engagement, communication, support and training, and practical issues.

Engagement:

- Information should be made widely available through a number of channels to ensure that service users and carers are informed of the opportunities for involvement;
- A range of different ways of being involved should be made available, in order to attract a wide range of service users and carers; this may mean adopting non-traditional approaches such as outreach or working with mediators from diverse communities;
- There should be a fair and transparent recruitment process;
- Role or job descriptions should be drawn up for involvement positions, whether they are paid or unpaid, employed or voluntary;
- Flexibility should be built in, to enable people to take advantage of different opportunities and to move in and out of involvement when they wish to or need to;
- Meetings should take account of those involved and should consider reasonable adjustments, such as not starting too early in the day in response to the difficulties experienced by some people taking psychotropic medication.

'We need to be involved at the very beginning, with the development of the service rather than just delivery.'

Communication:

Clear and regular communications should be adopted throughout an involvement activity;

- Jargon should be avoided – or clear and repeated explanations of terms and acronyms used should be given;
- Any written documents need to be sent out well in advance of meetings for people to have time to prepare;
- Feedback about the results or outcomes of an involvement activity should be given;
- Decision-making processes need to be open and accessible.

Support and training:

'If people don't have the support they feel they need, they may not feel comfortable to express themselves or [may be] overwhelmed, then it is really quite pointless' - Participant in NIP Consultations

Support for those involved needs to consider:

- Administrative support;
- Supervision;
- Emotional support;
- Opportunities for peer support or peer mentoring should be encouraged;
- Training should be given to enable equitable involvement and skills development;
- Training should be given to professionals/members of staff to raise awareness about involvement.

- Where possible, training should be shared by and with service users, carers and professionals taking part in an involvement process, as this can help to build a sense of team work.

Practical issues:

The policy, process and budget for the payment of fees and expenses needs to be clarified in advance of involvement;

- Information about payment of fees and 'out of pocket' expenses should be clear from the start; actual payment should be clear and timely;
- Childcare, carer and personal assistant costs should be taken into account when considering payment for people to become involved;
- Travel to be booked in advance where possible to avoid people being out of pocket.

IMPACT

'The end result should have outcomes or else what is the point? And we should be informed of these outcomes' - Participant in NIP Consultations

We are not interested in involvement for its own sake; for involvement to be meaningful, it must make a difference. It should lead to the improvement of services and the mental health and wellbeing of individual service users and carers. Becoming involved can also have a positive impact on the people who are involved (for example, by giving them the opportunity for increased skills and confidence). The purpose of involvement should always remain at the centre of any attempt to assess impact.

In order to assess the impact of involvement, the following questions need to be asked:

1. What were the intended outcomes of the involvement activity? (refers back to the purpose of involvement)
2. What actual difference(s) have service users and carers made to the project, activity or organisation? (This can be monitored by continuous recording

throughout a project as well as assessment at the end)

3. How did everyone feel about the process of involvement? (e.g. using 'end of involvement' questionnaires)
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 using the service?

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 (Further detail is given in the full report.)

'The end result should have outcomes or else what is the point? And we should be informed of these outcomes.'

Where 4Pi happens

A cycle of learning and influence...

We recommend taking a cyclical approach to assessing impact: involvement should be regarded as a continuous and shared learning process following a cycle of improvement or development: Act – Evaluate – Reflect – Learn – Act.

Some people may use the terminology: Plan – Do – Study – Act (PDSA) used in health improvement.

Another way of looking at this cycle of learning is given in the diagram below



Where involvement happens

In the main report, we explore involvement in the following areas:

A: Individual care and treatment

B: Community involvement

C: Operational (services, projects, training and education)

D: Strategic (commissioning, policy, service development)

E: Monitoring and evaluation

In each of these areas, we summarise the research evidence for the benefits of involvement, the evidence for good practice and give a summary of the guidelines and tools available for supporting involvement at each level.

This is a working document and a developing programme of work. We plan to add to our resources over the coming months: if you know of any useful tools, measures, guidance or guidelines to aid people in achieving good practice in involvement, please do let us know.

Contact us by email at info@nsun.org.uk or telephone 020 7820 8982.

‘I was really sceptical about being involved but have been surprised at how, if we are smart, can use involvement and really influence things.’

Our work

The full report on the 4Pi National Involvement Standards brings together the lessons and messages from the following sources of knowledge and evidence; most are available here: www.nsun.org.uk/about-us/our-reports-and-publications-we-refer-to-in-our-work/

- 1. Voices of Influence: Sounding out involvement – Raza Griffiths, 2013.** Report of consultations carried out during 2012; the NIP team consulted with 114 service users and carers at 10 consultations around England to inform the development of the involvement standards.
- 2. NIP Literature Review of Resources – Alison Faulkner, 2013.** This review was undertaken in order to scope the standards, measures, tools and guidelines for assessing or monitoring user and/or carer involvement.
- 3. Literature Review on Involvement – David Crepaz-Keay, 2013.** This literature review aimed to source evidence based characteristics of effective service user involvement that could be refined into indicators of effective involvement.
- 4. Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement – Jayasree Kalathil, 2008; reprint 2011.** The report of a consultation to explore the barriers to and solutions for meaningful partnership with service users and survivors from black and minority ethnic (BME) backgrounds in mental health user involvement initiatives.
- 5. A review of values-based commissioning in mental health – Emma Perry, Jo Barber and Elizabeth England, 2013.** This is a review of values-based commissioning in the West Midlands.
- 6. Advice and feedback from the NIP Advisory Group and the Management Group of partners.**
- 7. Report of a questionnaire consultation with service users and carers – NSUN, 2013.**
- 8. Unlocking Service User Involvement in Forensic Settings – NSUN/WISH, 2011.** Research into the provision of service user involvement in secure settings.

9. On Our Own Terms: Users and survivors of mental health services working together for support and change – Jan Wallcraft with Jim Read and Angela Sweeney, 2003. London: Centre for Mental Health.

10. Service users' experiences of recovery under the 2008 Care Programme Approach - Dorothy Gould 2012. Published by NSUN and the Mental Health Foundation.

11. The Making A Real Difference resources – produced under NIMHE/CSIP. All are now located on the NSUN network website.

Companion documents

The Language of Mental Wellbeing – Emma Perry, 2014

Service User Involvement in Health and Social Care Policy – Emma Perry, 2014

Mapping Black and Minority Ethnic Mental Health Service User Involvement – Jayasree Kalathil, 2014

Carer Involvement – Jayasree Kalathil, Karen Machin, 2014

With thanks

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An invitation to get involved

4pi National Involvement Standards



We are asking organisations to sign up to the 4Pi National Involvement Standards. Please visit the NSUN website for more information about who has signed up and how you can too. www.nsun.org.uk

The National Involvement Partnership (NIP) project supported this work with a three year grant from the Department of Health's Innovation, Excellence and Strategic Development Fund (IESD).

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