

National Involvement Standards

4PI

**together we
are stronger**

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Executive summary

The National Survivor User network (NSUN) hosts the National Involvement Partnership (NIP) project. The project aims to develop national standards for the involvement of service users and carers in mental health and social care services, and establish a national infrastructure for involvement. The aim is to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and care services. The project aims to share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates involvement. This project will promote user and carer leadership, realising the vision 'nothing about us without us'.

The National Involvement Partnership is led by NSUN and includes the 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.

This is a summary of the main report: The National Involvement Partnership 4PI National Involvement Standards (NSUN, 2013).

The NiP 4PI National Involvement Standards

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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.

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 capital.
- 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.

The 4PI National 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.

- Principles
- Purpose
- Presence
- Process
- Impact

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 needs to begin with the following shared principles and values:

- To bear in mind at all times that our ultimate goal is to improve services and to improve the mental health, wellbeing and recovery of individuals;

- The need to embrace inclusivity, equality of opportunity and fairness;

- A commitment to listen to service users and carers with respect and openness;

- A commitment to change in response to the views of service users and carers;

- Clarity and transparency from the start in all communications;

- Acknowledgement of the power differentials that exist between professionals and service users, and a commitment to minimise them where possible;

- A commitment to support race equality and to challenge discriminatory organisational practices;

- An open-minded approach towards cultural differences and diversity in ways of working;

- Sensitivity about language and actions: to acknowledge 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.’ [Kalathil, 2008/2011]

The purpose of involvement needs to be both clear and shared with all of the people who are engaged in the involvement activity. 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 clearly stated and agreed at the start, so that everyone connected with the involvement activity or organisation knows why service users and carers are being involved;
- Clarity about the purpose of involvement should be extended to individual roles and potential activities for service users and carers;
- Clarity and transparency needs to be shared about the potential for involvement and influencing, as well as the limits of influence;
- The intended outcomes for involvement 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 quoted in the Values-based Commissioning report]

- A diversity of service users and carers should be involved at all levels and stages of an activity, organisation or project .
- Service users and carers should be involved at all levels within the organisation, project or activity including at decision-making levels;
- 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.
 - At an early stage, an analysis of the population under consideration should be undertaken in order to ensure that the involvement activity reflects that population – and to ensure that people particularly affected by the service or issues

under consideration are actively approached for inclusion.

- There are monitoring procedures in place to monitor the presence of service users and carers, and the diversity of those involved, throughout these levels.
- Potential roles for service users and carers within organisations were identified in the previous NIP work (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
 - Expert by experience
- 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/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.

Process

“We need to be involved at the very beginning, with the development of the service rather than just delivery” (Participant in the NIP Consultations)

The involvement process needs to be carefully planned and thought through, in order to ensure that service users and carers can make the best possible contribution. 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.

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 the NIP Consultations)

- Support for those involved needs to consider:
 - Administrative support,
 - Supervision, and
 - 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 the 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 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?

Impact needs to be explored in the following areas:

(further detail is given in the full report)

- Ethos/culture
- Policy and Planning
- Delivery
- Outcomes and outputs
- Diversity and equality of opportunity
- The service user and carer experience of the service

We recommend taking a cyclical approach to assessing impact: involvement should be regarded as a continuous process and follow a cycle of improvement or development: Act – Evaluate – Reflect – Learn – Act cycle. Some people may use the terminology Plan – Do – Study – Act (PDSA) used in health improvement technologies.

Where involvement happens

In order to explore further the evidence for service user and carer involvement in mental health services, we have explored involvement in the following areas, including a section on monitoring and evaluation which is relevant to all:

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 the full report, we summarise the research evidence for the benefits of involvement in each of these areas, the evidence for good practice and give a summary of the guidelines and tools available for supporting involvement at each level. In order to assess the impact of involvement, service users and carers should be involved throughout the monitoring and evaluation process, from setting the goals through to analysis and interpretation of the impacts

identified. In the full report we recommend ways of doing this and a number of tools that can assist.

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 details]

“I was really sceptical about being involved but have been surprised at how, if we are smart, how we can use involvement, we can really influence things.” [Service user quoted in the consultation report ‘Voices of Influence’ – Raza Griffiths, 2013]

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:

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. Over 50% of participants were from BME. [LINK]

2. NIP Literature Review of Resources – Alison Faulkner, 2012.

This review was undertaken in order to scope the standards, measures, tools and guidelines for assessing or monitoring user and/or carer involvement. [LINK]

3. Literature Review on Involvement – David Crepez-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. In combination with the Review of Resources (above), the aim was to ensure that what we propose in the involvement standards is based on solid evidence. [LINK]

4. Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement – Jayasree Kalathil, 2008; reprint 2011.

The original report, published in 2008, is the report of a consultation to explore the barriers to and solutions for meaningful participation of service users and survivors from black and minority ethnic (BME) backgrounds in mental health user involvement initiatives. The review in 2011 sought to assess progress and to look at the current status of black and minority ethnic user involvement in mental health. [LINK]

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. It reports an evaluation of the West Midlands mental health commissioning modelling group and consultations with service users and carers.

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. [LINK]

8. Unlocking Service User Involvement in Forensic Settings – NSUN/WISH, 2011.

Research into the provision of service user involvement in secure settings. [LINK]

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. The Making A Real Difference resources – produced under NIMHE/CSIP. All are now located

on the NSUN network website. www.nsun.org.uk

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