4Pi National Involvement Standards

This report sets out its main tasks as developing national involvement standards in mental health and hardwiring involvement into the planning, delivery and evaluation of mental health services.

Involvement for influence

Principles **Purpose** **Presence** **Process** **Impact**

Principles Purpose Presence Process Impact

Contents

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Foreword

This report sets out its main tasks as developing national involvement standards in mental health and hardwiring involvement into the planning, delivery and evaluation of mental health services.

The key themes of equalising power, recognising diversity, and commitment to genuine change have been around since service users and family members first began to challenge the apparently godlike power of consultant psychiatrists and medically-dominated mental health systems. Since the option of abolishing psychiatry and re-inventing a mental health system which did not stigmatise and damage people was not readily available, many began to try to reform the existing systems from the ground up, daunting though this appeared in the 1970s and early 80s.

In a talk I gave in 2010 at the Mental Health Congress, I compared service user involvement to the labours of Sisyphus who was condemned to continually push a boulder up a hill, only for it to roll back down to the bottom.

I have seen how often service users take up involvement opportunities, only to become disillusioned and cynical when nothing seems to change. Service users worked for involvement through a succession of national organisations, beginning with the Community Health Councils, which were abolished in 2003, then Patient and Public Involvement, abolished in 2008, then LINks, abolished in 2010, and now HealthWatch. Each time it feels as though we are at the foot of the mountain and starting again from scratch. We urgently need some continuity, through national systems and standards, and proper means of evaluating the outcomes of involvement, to retain and build on what is learned by doing.

Despite witnessing many bad examples of involvement, where service users and carers have encountered tokenism and visible or hidden barriers, I have also seen some good examples of what can happen when involvement is properly supported and in place from the outset. This has been particularly so in some mental health research, where service users and carers have been part of projects from the outset, shaping the questions, deciding on the methods and outcomes to be sought, and getting involved in every stage including the dissemination of results. Also, the provision of statutory funding of service user and carer involvement in social work education enabled involvement which had a real influence on trainee social workers.

This report stands on the shoulders of giants, in Isaac Newton's famous phrase. Not only does it build on its own consultations, but it brings together a wide range of learning from service user and carer-led involvement work. It draws together sets of standards developed alongside service users and carers by a range of organisations including the National Institute for Mental Health in England, the Centre for Mental Health (formerly the Sainsbury Centre) and Mind. It also includes the results of reports such as Kalathil's 'Dancing to Our Own Tunes', and the work of Catch-a-Fiya, based on BME service users' experiences. So there is now a strong and clear basis for national standards which are rooted in the work of generations of service users and carers, supported by the statutory and voluntary sector. No longer can there be excuses for not knowing how to do involvement properly, the tools for the job are contained in this report.

Following the report's introduction, setting out the vision, the second section traces the policy context, history and underpinnings of involvement. The third section contains the NIP's national involvement standards, in terms of principles and purpose for involvement, the actual presence of service users and carers in their real diversity and at all levels, the processes of involvement and the impact of involvement (the acronym PPPPI now referred to as 4Pi). The fourth section sets out an impressive range of evidence in the form of research results, examples of good practice, and sets of tools and guidelines. This section provides a wealth of information, pdfs and websites which should ensure that anyone seeking guidance on how to do involvement well can find something practical to help them here. The fifth section revisits the key themes and principles, with backup from the evidence base for each theme. Finally, the conclusion reinforces the message of a partnership of shared expertise.

So, to all commissioners and anyone who is serious about ensuring that involvement, participation, engagement, co-production, partnership, or whatever the currently fashionable phraseology happens to be, is genuine, and no longer a cynical tick-box exercise, please put a copy of this report on your real or virtual desktop and refer to it regularly. Take the tools from this toolkit, use them and share the results so that we can continue to develop this work and take it forward. No more labours of Sisyphus; let's have involvement that makes a real difference!

Jan Wallcraft
Survivor researcher at Wolverhampton University and lead author of On Our Own Terms

A note on terminology

BME: There is often a debate around the terminology used to refer to communities minoritised in relation to the local population on the basis of their 'racial' or 'ethnic' origin. No single term is fully capable of capturing the vast diversity, difference and similarity within these communities (Kalathil, 2008). Currently, 'black and minority ethnic' is the term consistently used in census, survey and routine administrative data. This term refers to a range of communities including established groups (e.g. African, Asian, African-Caribbean), 'new' migrant communities (e.g. people from Eastern European countries), refugee and asylum seeker communities, transient communities (e.g. the traveller community), and groups often referred to as 'invisible minorities' (e.g. the Irish community). Hence we have chosen to use this term for the purposes of this review and report.

Service user: The NHS has traditionally referred to people who use their services as 'patients'. However, in recent years the term has received criticism in the field of mental health. Some individuals, particularly those with long-term conditions, have argued that the term 'patient' is patronising and incorrectly positions them as passive recipients of care (Coldham, 2012). Many people who have experienced mental ill health define themselves as 'survivors', not only of the effects of mental health conditions, but of the psychiatric system (Stickley, 2006). However, the most recent and common term used by policy makers and practitioners to describe those on the receiving end of mental health services is 'service user' and so we use this term here. We acknowledge that this term does not suit everyone.

Carer: Family members, partners, spouses and children who come to care for their relative who experiences mental health problems, do not necessarily call themselves 'carers'; they may view the support they give simply as a part of their natural relationship or family responsibility. It is more accurate to refer to people who undertake these roles as 'families, friends and carers' (Sayce et al, 2012) The fact that the term 'carer' has become common parlance may mean that many people are missed out of initiatives aimed at supporting them. Where we use the term 'carer' in this report, we do so with full acknowledgement that this can cover many different roles and relationships in relation to individuals with mental health problems.

Involvement: The language and the landscape of service user and carer involvement has changed over the years. Different words are used by different organisations at different times, for example: consultation, participation, engagement, co-production. Some terms imply a greater level of 'involvement' or influence in an organisation or activity; however, sometimes the language does not reflect the underlying ethos or purpose. More recently, the term 'leadership' has become more prevalent amongst service users and user-led organisations. By leadership, we mean that service users and carers take the lead in determining policy or service development, individual care and recovery. In this report we have largely retained the use of the term 'involvement' for ease of understanding, but other terms are used where it is thought relevant to do so.

1. Introduction

'One danger in talking about service user involvement is that it is frequently taken to mean mental health professionals involving service users rather than service users involving themselves'. (Campbell, 2008)

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). One of the main aims of this project was to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and social care services. The work builds on the previous NIP work (Faulkner, 2009; Robotham and Ackerman, 2011[1]), and aims to share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates involvement.

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 project demonstrates user and carer leadership, realising the vision 'nothing about us without us'[2].

This report is a comprehensive account of the knowledge and evidence supporting what we know about the meaningful involvement of mental health service users and carers – in their lives, communities and in mental health and social care services. It is intended for everyone for whom involvement is important, as well as for those who remain to be convinced. We hope that people will be able to use it to find the resources they need to make meaningful involvement a reality for them, whether locally or nationally.

The work of the NIP originated in a contract to supply service user and carer involvement at all levels of activity of the National Mental Health Development Unit (NMHDU - part of the Department of Health) until March 2011. It was led by NSUN and included the organisations: Afiya Trust, Attend, Equalities National Council, the Mental Health Foundation, Social Perspectives Network (SPN) and Together for Mental Wellbeing. This work was independently evaluated by the Mental Health Foundation (Robotham and Ackerman, 2011).

The follow up three year programme of work called 'Involvement for Influence - Influence for Improvement' was funded by the Department of Health's voluntary sector funding for health and care projects. The first stage of the work included a literature review, review of resources, consultations around the country in order to help us develop the framework, and involvement and influencing events. The project brings together all of the knowledge and expertise about involvement, built up over the last few decades, in one place.

Focused work was carried out in three pilot sites in England, with the long term aim of building an independent service user-led national involvement infrastructure that will not disappear or disintegrate when statutory services are restructured.

Our Vision

The core purpose of service user and carer involvement must be to improve people's lives, a key part of which is to improve mental health services and how each of us experiences those services, if and when we need them. All involvement needs to have that core purpose in mind at all times. Developing good practice policies and procedures for involvement has no meaning if those policies and procedures do not reach the individual who is admitted to hospital today, tomorrow or next week.

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;

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1. Both reports are available on the NSUN website www.nsun.org.uk
2. Although this term came into common usage by UK disability activists in the 1990s, there is evidence to suggest that its roots go further back. It was used as the title of a book by James Charlton, an American disability rights activist, in 1998.

One danger in talking about service user involvement is that it is frequently taken to mean mental health professionals involving service users rather than service users involving themselves.

- 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.

This Report

This report presents the 2015 version of the NIP 4Pi standards for involvement (Principles; Purpose; Presence; Process; Impact). The aim of the 4Pi standards is to provide a framework, both for establishing good practice in the involvement of service users and carers in mental health care, service delivery and policy, and for monitoring and assessing that involvement. Our previous work for NMHDU gave us the original PPPI standards. This report represents the result of revising these standards to become 4Pi (with the addition of Principles), through bringing together the lessons and messages from the following sources of knowledge and evidence, along with a detailed analysis of the policy background:

1. Voices of Influence: Sounding out involvement – Raza Griffiths, May 2013. Report of consultations carried out for the NIP project during 2012 (referred to in this report as the Consultation Report). From September to November 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 black and minority ethnic communities.

2. Voices of Influence: Sounding out involvement – Raza Griffiths, June 2013. Report of a questionnaire consultation with 43 respondents, to supplement the above consultation.

3. NIP Literature Review of Resources – Alison Faulkner, 2013 (referred to in this report as the Review of Resources). This review was undertaken in order to scope the available evidence, originating mainly from service users and carers, to support and inform the development of national standards on involvement. The focus was on finding standards, measures, tools and guidelines for assessing or monitoring user and/or carer involvement.

4. Literature Review on Involvement – David Crepaz-Keay, 2013 (referred to in this report as the Literature Review). 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.

5. Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement – Jayasree Kalathil, 2008; reprint 2011 (Referred to in this report as DTOOTs). 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. It includes a charter and guidelines with recommendations for good practice in increasing involvement of and partnership working with service users and survivors from black and minority ethnic backgrounds.

6. A Review of Values-Based Vommissioning in Mental Health – Emma Perry, Jo Barber and Elizabeth England, 2013 (referred to as the

Nothing about us without us

MARD Project was undertaken in direct response to the HASCAS[3] review of service user and carer involvement in the National Institute for Mental Health England (NIMHE). The series of documents and guidelines produced under the MARD programme by many service users, carers and others involved in NIMHE and the Care Services Improvement Partnership (CSIP) demonstrate the potential for this kind of work to disappear when Government departments are restructured or organisations dissolved. A full list of these documents appears in the NIP Literature Review of Resources and they are all available to download from the NSUN website.

At NSUN we shall continue to collect resources and to build our evidence base for involvement. To this end, we welcome contributions from anyone and everyone who is doing similar work. ●

VbC Report). This is a review of values-based commissioning in the West Midlands. It reports on an evaluation of the West Midlands mental health commissioning modelling group and consultations with service users and carers.

7. Advice and Feedback from the NIP Advisory Group and the Management Group of partners. [See appendix A for membership of the Advisory Group]

8. Service Users' Experiences of Recovery Under the 2008 Care Programme Approach - Dorothy Gould 2012. Published by NSUN and the Mental Health Foundation.

9. Unlocking Service User Involvement in Forensic Settings – NSUN/WISH, 2011. (referred to as the WISH Report). Research into the provision of service user involvement in secure settings.

10. 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.

Making a Real Difference (MARD)

In addition to these ten key pieces of work, a major source of knowledge for the work of NIP is the Making a Real Difference (MARD) programme of work. The

3. Health and Social Care Advisory Service www.hascas.org.uk

2: Policy context for involvement

This chapter outlines the policy context for service user and carer involvement in mental health and social care services. It includes the following sections:

• **The Policy Context**
• **Service user/survivor movement and involvement**
• **The involvement of family, friends and carers**
• **The changing language of involvement**

The Policy Context

Policy relating to the involvement of service users and carers in health and social care services dates back at least as far as the 1980s. The 1990 NHS and Community Care Act (Department of Health, 1990) introduced a focus on the 'consumer' and assumed that greater choice would be brought about – both by market mechanisms and through consumer feedback, which would direct the kind of services that purchasers would then demand of providers. The assumption was made that involvement would improve the relevance and quality of services for the consumer. The Act was the first piece of UK legislation to establish a formal requirement for user involvement in service planning and it made consultation with service users and carers a requirement for local authorities. This applied as much to the individual and their care as to the wider provision of services.

This was followed in the 1990s by, for example: The Patient's Charter 1991 (which also stresses consumerism), The Health of the Nation 1992 (which highlighted the importance of service user consultation in the planning and evaluation of services), the National Service Framework for Mental Health (1999) and Patient and Public Involvement in the new NHS (1999). In 2000, the NHS Plan (Department of Health, 2000) discussed how user involvement in the NHS could bring about a 'patient-centred service'.

In social care the principle for involvement is integral to the core legal mandates for social care services. As stated above, the NHS and Community Care Act 1990 refers to the need to inform, consult and involve service users. Subsequent legislation, for example the Health and Social Care Act 2001, made provision for direct payments of social care monies to be made to eligible persons to enable them to directly purchase services or support to meet their needs. This is potentially an example of user involvement in their own care, with the control handed over to the service user. The health equivalent to this, personal health budgets, is currently being piloted across the country.

The National Health Service Act 2006 consolidated much of the legislation concerning the health service, and stated that health services must make arrangements to involve their service users, whether directly or through representatives, in the planning, development and decision-making processes of their services. Furthermore, since October 2010 both NHS and independent hospitals have had to comply with the new Essential Standards of Quality and Safety (CQC, 2010). These include the requirement that hospitals in both sectors ensure 'service users are enabled to make, or participate in making, decisions relating to their care or treatment'. The guideline goes on to set out the assessed outcome that service users in all hospitals are encouraged to express their views and these views should be accommodated as far as is appropriate or reasonably practicable.

The White Paper 'Equity and Excellence: Liberating the NHS' (2010) set out the Government's vision of a NHS that puts patients and the public first, based on the principle 'no decision about me, without me', an amended version of the principle that originates from disability activists 'nothing about me without me'. 'Equity and Excellence' included proposals to give everyone more say over their care and treatment with more opportunity to make informed choices. It is also notable that the National Institute for Health and Care Excellence (NICE) – the body that provides evidence-based guidance and advice for health, public health and social care practitioners – has a strong public involvement programme.

For the first time in the history of the NHS, the NHS

Constitution brings together in one place information about what staff, patients and the public can expect from the NHS. Amongst other things, it states:

'You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services'. (Section 3a of the NHS Constitution, p72).

The cross-government mental health outcomes strategy 'No Health without Mental Health' (2011) places an emphasis on wellbeing and on outcomes for individuals, based on principles of 'freedom, fairness and responsibility'. This document also draws attention to the importance of equality and human rights, pointing out that there is clear evidence that mental health services do not always meet the needs of certain groups, particularly black and minority ethnic communities and older people.

Family, friends and carers

Carers and family members have been mentioned in much of the policy guidance alongside service users; for example in the mental health strategy document 'No Health Without Mental Health' :

'families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered'. (DH/HMG 2011, para 4.20).

The Carers (Recognition and Services) Act, introduced in 1995, could be seen as the first official recognition of the role and needs of carers. Although the Act does little in terms of recognising the involvement of carers in how services are run, it recognised their right to an assessment of their own needs and support. Standard 6 of the 1999 National Service Framework for Mental Health addressed 'caring for carers'. The objective of standard 6 was to ensure that health and social services regularly assessed the needs of those who were providing regular and substantial care for a person on the Care Programme Approach (CPA).

The Carers Equal Opportunities Act 2004 changed carers' rights in important ways. Under this Act, social services departments had a duty to inform carers of their right to an assessment. The Act further stipulated that the purpose of the assessment was not only to help the carer continue to care but also to discuss their wishes in terms of work, education, leisure etc. – in short, their requirements outside of their caring responsibilities. Further, under the Act, social services departments could now ask other public bodies including local health organisations to provide services for carers.

NIMHE (the National Institute for Mental Health England) published a range of documents in 2002-4, including Valuing Carers (the Mental Health Carers Charter), A Guide for Carers and a handbook for professionals working with carers. The Mental Health Carers' Charter proposes that:

- Carers' role and expertise are recognised and respected

- Carers are given the information and advice that they need

- Carers are involved in planning and agreeing the care plan for the person for whom they care

- Carers' individual needs are recognised, responded to, and reflected in the care plan

- Carers receive appropriate help and support when they need it

- Carers are actively involved in the planning, development and evaluation of services

Of particular significance to carers now is the refreshed Carers' Strategy (DH, 2010) which sets

> *You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies...*

out the Government's vision to involve carers from the outset in designing local care provision and in planning individual care packages; to enable them to fulfil their educational and employment potential; and personalise support for carers and those they support, 'enabling them to have a family and community life'.

In partnership with the Princess Royal Trust for Carers and the Acute Care Declaration consortium, the Government published 'The Triangle of Care – Carers included: A guide to best practice in acute mental health care', which sets out six key elements of good practice for mental health professionals working with carers. The principle behind the Triangle of Care model is simple: it honours the bond between the service user and carer that, in most cases, pre-exists the relationship between the service provider and service user and enables their full involvement in care and support, decision making and service delivery. The guidance, updated in 2013 (Worthington et al, 2013), emphasises the need for staff to become 'champions' for 'better partnership working and being able to challenge practice that excludes carers' and the need for an 'inclusive attitude' where carers and families 'are listened to and really heard and consulted more closely' (p.3).

Commissioning

The commissioning landscape has undergone considerable change recently. The Health and Social Care Act (2012) introduced duties for the new NHS England and Clinical Commissioning Groups (CCGs)

in April 2013, replacing Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs). CCGs have a legal duty to involve service users and ideally will have a named GP to provide a clinical perspective on the commissioning of mental health services. NHS England will assess the quality of commissioning carried out by CCGs. They will also commission GP services and many specialist mental health services. Further to this NHS England and the CCGs have a duty in relation to promoting involvement of each patient in decisions related to the prevention and diagnosis of illness and any care or treatment they receive. NHS England has a duty to issue guidance to CCGs on involvement. A comprehensive guide aimed at helping CCGs and other commissioners of health and care services to involve patients and carers in decisions relating to care and treatment was published in September 2013: 'Transforming Participation in Health and Care' www.england.nhsuk /wp-content/uploads/2013/09/trans-part-hc-guid1pdf

Rights and legislation

One of the fundamental dilemmas behind all of the policy guidance to emerge from succeeding Governments, is the tension between some of the 'progressive' policies, in which the patient is ostensibly at the centre of concern, and the more punitive discussions around risk where members of the public and public safety are the priority. Discussions around services being 'safe, sound and supportive' (with the emphasis on safe) began with Modernising Mental Health Services (Department of Health, 1998). Subsequently the Mental Health Bill (2002) introduced new powers of supervised community treatment or community treatment orders (CTOs), which permits the recall of people to hospital if they do not comply with conditions imposed upon them at the point of discharge. This became part of the Mental Health Act (2007).

This contradiction at the heart of policy continues to the present day and will continue to do so for as long as it is possible for people to be legally detained and treated against their will.

However, there is other legislation that can be used to protect people's rights. The Mental Capacity Act 2005 (MCA) created a framework to provide protection for people who cannot make decisions for themselves. It contains provision for assessing whether people have the mental capacity to make decisions, procedures for making decisions on behalf of people who lack mental capacity and safeguards. The underlying philosophy of the MCA is that any decision made, or action taken, on behalf of someone who lacks the capacity to make the decision or act for themselves must be made in their best interests (www.mind.org.uk).

The Equality Act (2010) brought together many separate pieces of legislation into one single Act, with the intention of providing a more streamlined legal framework to protect the rights of individuals and advance equality of opportunity for all. The Act strengthened protection for disabled people and for people discriminated against 'by association', i.e. family members and carers of disabled people.

The Human Rights Act (HRA) 1998 goes some way towards protecting the rights of people with mental health problems; Article 5 (the right to liberty) can be key to ensuring that use of detention is 'proportional and appropriate' and Article 6 (the right to a fair trial) can help to ensure a timely appeals process. According to Whitelock (2009), Mind uses the HRA to call for better access to healthcare for refused asylum seekers who are currently denied NHS care.

The UN Convention on the Rights of Persons with Disabilities (ratified by the UK Government in 2009) asserts that disabled people have human rights along with everyone else and that they should be able to enjoy them on an equal basis with non-disabled people. It goes further than the HRA by recognising that disabled people continue to face a wide range of barriers to realising their human rights in practice, and sets out the measures governments are expected to take to remove them and to ensure that the rights of disabled people are protected. The Equality and Human Rights Commission has published a guide to the implications of the Convention to people with disabilities in every day life (EHRC, 2010 'The United Nations Convention on the Rights of People with Disabilities: What does it mean for you?').

The service user/survivor movement and involvement

Over the last few decades, service users have increasingly organised themselves and campaigned to have a greater influence upon services and policy. In the mid-1980s the voices of protest became recognisably organised as a user or survivor movement. Initially the formation of hospital based Patients' Councils and a proliferation of user-led self-help and advocacy groups developed alongside the formation of organised networks in the 1990s such as Survivors Speak Out, the Hearing Voices Network and the UK Advocacy Network. The number of local service user groups increased quickly in the 1990s in response to some of the policy developments noted above, which enabled them to have a voice and a role in local service developments. Equally, some groups remained independent of such developments, preferring not to become involved in influencing to improve services but to campaign from outside or develop their own activities or services.

An outline of the history and position of the service user/survivor movement by Peter Campbell was published in the book 'Beyond the Water Towers' (2005) by the Centre for Mental Health. Campbell points out that much of the campaigning energy of the user/survivor movement in this country has been directed at existing psychiatric services and treatments, motivated by the desire to change and improve them, which is perhaps why 'user involvement' has become such a major development in the UK. Sometimes this has meant directing less energy towards user/survivor-led alternatives. Much of this history is preserved by survivor historian Andrew Roberts on the Survivors' History website: http://studymore.org.uk/mhhtim.htm.

A valuable overview of the service user/survivor

movement was published by the Centre for Mental Health in 2003 (On Our Own Terms; Wallcraft et al, 2003). This report, based on a survey of user groups across England, found that most of the groups they identified were engaged in some form of involvement activity relating to health and social care services. However, they also placed a high priority on providing mutual or peer support to their members. This report in many ways prepared the way for the establishment of NSUN. It recommended that a national network be established to support capacity building amongst local groups and to promote structures and policies to promote service user involvement.

'On Our Own Terms' also highlighted the failure of the user/survivor movement to successfully engage with black and minority ethnic service users and service user groups. Begum (2006) suggests that one reason for the dearth of 'involved' BME service users is the tendency of services to side-line them in favour of approaching BME professionals, community leaders or voluntary sector organisations to represent their interests. Trivedi (2009) explored these issues in relation to her personal experiences of involvement, which included membership of the black user group SIMBA. SIMBA became involved in a range of local activities on its own terms and in ways that encouraged black service users to take part (Trivedi, 2002). Trivedi concluded, amongst other things, that there is a need to recognise and address the impact of personal and institutional racism, and to explore the role and power relations between service users and mental health professionals in 'user involvement' settings. An additional issue that Trivedi highlighted as affecting the involvement of BME service users in generic 'user involvement' activities is that they may find it hard to raise issues of race and racism because they are perceived as having a 'chip on their shoulder', particularly if they are the only black person present (Trivedi, 2002; 2009).

A significant development in BME service user involvement was the establishment of the Catch-a-Fiya network by the Afiya Trust in 2006. The main aim of the network was to bring together service users from BME backgrounds around the country and provide a forum for networking and information sharing. Catch-a-Fiya worked to build the capacity of service users to participate in user involvement activities, to advise on changing service delivery within their trusts, to influence policy change through taking part in consultations, and take up discrete research and review work on matters that affect BME service users.

NSUN undertook to address some of the issues highlighted by Wallcraft, Begum, Trivedi and others by commissioning the consultation that resulted in the report 'Dancing to Our Own Tunes' (Kalathil, 2008). The recommendations from this report have been adopted by NSUN for this work and for future NSUN and NIP work. In a position paper on the Catch-a-Fiya network written in 2009, Kalathil highlights the need to consolidate the voice of BME service users/survivors. One of the ways of doing this that she identified was to take forward some of the ideas identified in the report 'Dancing to Our Own Tunes', for example: the creation of a life story archive, a 'count me out' census, mapping BME groups and their work nationally, and evaluating user involvement.

'If there has to be meaningful involvement of service users/survivors from black and minority ethnic communities in mainstream initiatives, there has to be structural changes in hierarchies, ways of working, assumptions, power structures within institutions, resource allocation, the location of decision making, and the way people are treated within mental health services and outside them.' (Kalathil, 2008 p 12)

One of the implications of working in this way is for us to widen the horizon of our understanding of involvement to incorporate what might be termed 'community involvement' (see Chapter 4). As Kalathil points out, people, groups and communities use different language to describe both their experience of distress and the ways in which they work to influence their own and their community's mental health. These different ways of working may include models such as community development and advocacy, and focus on strengthening the resilience

of the immediate community instead of, or as a precursor to, involvement in services.

Another implication of this way of working is to embrace a 'rights-based' approach to involvement and participation. In 'Dancing to Our Own Tunes', Kalathil (2008) drew attention to the need to see BME 'involvement' within a broader social context: to link change to mental health services with changing the overall social and political situation of black and other minority ethnic groups in this country. In her later review of this report (Kalathil, 2011), she found that the potential of this rights-based approach is currently under threat – due to increases in the use of compulsion under the Mental Health Act and the detrimental effects of changes to the welfare benefits system by the coalition Government.

'People's ability and interest in taking part in user involvement activities is diminished when their ability to meet their basic needs is itself threatened.' (Kalathil, 2011 p.16)

Our hope and our intention in consolidating this work within the 4Pi standards is that we will help to create a new platform for involvement that will encourage and promote more equitable involvement. NSUN is also mapping BME service user/survivor activity over the coming months in order to develop the next phase of the work. This will include developing the potential for further networking and capacity-building with BME service users and user groups.

The involvement of family, friends and carers

Much of the history of mental health carer involvement is rooted in the broader generic carers' movement. In the UK, it is generally considered that the Reverend Mary Webster, who, in 1954 at the age of 31, gave up her work to care for her parents was the person who began the carers movement in the UK. She drew attention to the plight of unmarried women with dependants and in 1965 formed the National Council for the Single Woman and her Dependants. The Council won the first ever legislative change with the 1967 Dependant's Relatives Tax

Allowance. In 1976, the Council led the campaign for the Invalid Care Allowance based on the report The Costs of Caring. This is seen by many as the first example of targeted research leading to change in issues concerning carers.

The Association of Carers was set up in 1981 by Judith Oliver, who cared for her disabled husband. According to Carers UK, an important early principle of the Association was that 'carers themselves are best placed to decide what help they need', the idea we know today as 'experts by experience'. In 1988, the Council and the Association merged to form Carers National Association, which was renamed as Carers UK in 2001. The main focus of the movement throughout its history has been campaigning for the rights of carers, achieving legislative change and placing the real life experience of carers at the heart of policy and practice change.

Rethink Mental Illness (formerly the National Schizophrenia Fellowship) was formed by carers and family members in 1972, initiated by a letter to the Times by John Pringle. He described, not just his own situation as the father of a son with a diagnosis of schizophrenia, but also the wider issues facing others in similar situations. He called for better social care and for unified policies to bring together the fragmented support then on offer to people with long term mental health problems. People responded to his letter and met up and began to work together:

'We left those meetings feeling stronger and more confident. We were like a little community, we were united, and we were together. Our first meeting, packed into a small west London flat, was the start of something big. Our group became the national charity Rethink Mental Illness.' [Ernestine Adams, a founder member, quoted on the Rethink website.

Specific barriers affecting carers from BME communities, stopping them from meaningful involvement and in getting the support they needed were influenced by two key attitudes: the idea that BME communities were 'hard to reach' or were not interested in getting involved, and the assumption

that BME communities 'looked after their own'. In addition, the experience of black and minority ethnic carers also tend to be compounded by structural racism, an assumption of homogeneity within BME communities, and language barriers.

The National Black Carers and Care Workers Network (NBCCWN), hosted by the Afiya Trust, was established in 1998 to address these concerns. NBCCWN aimed to research and report issues affecting BME families and carers, produce good practice guidelines, influence policy and practice and provide a national platform for bringing together carer voices from ethnic minority communities. Structural issues not fully addressed in mainstream involvement activities and movement affect carers from other marginalised communities too. For example, carers from LGBT groups, disabled carers and older carers have all identified and voiced issues such as invisibility in social policy, structural disadvantages including prejudice and discrimination, and a lack of attention to intersecting socio-economic, political and cultural identities and disadvantages.

As with the service user/survivor movement, it is important to remember that carers are not a homogeneous group. They have different relationships with the person they care for, may have different views and different priorities which make it important to involve service users and carers separately. However, service users and carers may also be able to work together effectively on issues that unite them. Tensions have been identified in relation to the issue of confidentiality which can often be used inappropriately by professionals to exclude family members, but may equally be an important principle to service users in a move towards independence. The Values-Based Commissioning report (Perry et al, 2013) identified the need to address service user and carer involvement separately, and this recommendation has been incorporated into our standards under Presence. However, there may be issues at a local level that make it more sensible to unite the involvement of service users and carers.

The changing language of involvement

In recent years, the emphasis has moved away from 'involvement', and towards more equal partnership working and the 'co-production' of services (Stickley, 2006); (see also Practical Approaches to Co-production; Department of Health, 2010). Arguably, traditional models of involvement perpetuate the power imbalances inherent in mental health services and so fail to change them. Co-production, it is argued (e.g. by the New Economics Foundation www.neweconomics.org), can create a new platform in which stakeholders come together as equal partners with acknowledgement of each partner's expertise and skills. However, as found by the NSUN report on values-based commissioning (Perry et al, 2013), co-production requires a major culture shift in an organisation. As with involvement, co-production can still be dictated by the agenda of the body holding the power – usually the provider, commissioner or Government itself.

In recent years, there has been another concept change in relation to involvement; we now promote the idea of service user and carer leadership, to reflect the fact that it is our experience and expertise that should take the lead in service design, development, delivery and mental health policy. Service user/survivor leadership, as described by Mary O'Hagan (2009) is based on an ethos of empowerment and equality and recognises that there are a variety of leadership roles in the collective user/survivor or mental health settings. Leadership in one's own recovery includes shared leadership with the mental health workers involved in providing a service. The promotion of service user and carer leadership involves developing training in order to build our capacity and confidence to take an active role in involvement, development and change and in our own recovery. A useful document that discusses these issues is the Making a Real Difference (MARD) document 'Leadership Recommendations: Strengthening the support available to people who become involved by making appropriate training available' (NIMHE/CSIP 2007). ●

3: The 4Pi National Involvement Standards

This chapter presents the 2015 revised version of the NIP national involvement standards, based on the previous work that resulted in PPPI. Adding a new 'P' to our standards in the form of Principles, gives us 4Pi:

- **Principles**
- **Purpose**
- **Presence**
- **Process**
- **Impact**

Principles

Meaningful involvement starts with a foundation of shared principles and values. The importance of having clear and shared principles and values at the basis of involvement is emphasised in Dancing to Our Own Tunes (DTOOTs), in the Review of Values-Based Commissioning in Mental Health (VbC report), the Consultation report, the Questionnaire report and in many of the guidelines reviewed for the NIP Review of Resources.

'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)

A strong theme to emerge from all of the reports is the need to embrace cultural diversity and race equality through an acknowledgement of racism and awareness of diverse values, understandings and ways of working. Indeed, values and principles are particularly emphasised by service users and others writing from a BME perspective; the experience of racism seems to call upon a greater need for shared values in approaching involvement or partnership working.

Basic values proposed include respect, inclusivity, equality and fairness. A significant theme is the need for services/professionals who are involving people to listen actively to service users with a genuine commitment to share power, and to act and change in response to the views of service users and carers. Coupled with this is the need to be open and honest about the limits of influence; for example, in the VbC

> *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.*

report, to be open about the constraints on funding that might limit the influence that service users can have on decisions. The importance of principles is to allow for a relationship of trust to be established between the partners or stakeholders engaged in the involvement process.

Principles:

- To bear in mind at all times that our ultimate goal is to improve people's mental health, wellbeing and recovery, a key part of which is to improve services and people's experience of those services;

- 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

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.

Many of the reports and guidelines reviewed for the Review of Resources recommended being clear about the purpose of involvement. One of the reasons given for this is to avoid tokenism or involvement for involvement's sake rather than as a means to bring about change. A clear statement of purpose can ensure that everyone knows why service users and carers are being involved and that the involvement has meaning to everyone. Used well, it can also ensure that the potential benefits of involvement are communicated to everyone, again in order to ensure that everyone understands the purpose for involving people.

The NIP consultations found that service users and carers would like to extend the purpose of involvement to incorporate the promotion of recovery and to challenge stigma and discrimination. The VbC report emphasised the importance of managing expectations: being explicit about what cannot be changed, not raising expectations beyond what

> *I think they ought to be involved at the highest level... We can all be involved at all levels and that would really make it work, I think.*

is realistic, but equally, being positive about what can be achieved through involvement. Clarity and transparency about the purpose of involvement from the start can also help to build trust between partners which is an essential plank of successful involvement, particularly for diverse and marginalised communities.

Purpose:

- 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 VbC report)

A diversity of service users and carers should be involved at all levels and stages of an activity, organisation or project[4]. Most of the reports listed at the start of this document (DTOOTs, the Consultation Report, the Review of Resources, On Our Own Terms and the VbC Report) strongly advocate the need for more people from diverse backgrounds to be involved. (This is against a background of observing

4. 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. Nevertheless, the aim should be for involvement at all levels.

mainly white, middle class, educated service users being involved in, for example, commissioning). The different methods for addressing this are included under Process.

Robson et al (2005) in 'Developing User Involvement: Working towards user-centred practice in voluntary organisations', report that the presence of service users can enable organisations to change through providing opportunities for service users to influence formal decision-making processes; become part of networks of users and others; and to learn about each other's experiences and priorities. However, their research found that presence without influence is also possible – and that this manifests tokenism. To guarantee responsive service development, service users need to have a high presence and a high level of influence.

The Consultation Report emphasises the need for service users and carers who are involved in an activity to be linked with, or accountable to, a wider constituency of service users and carers in order to ensure that more people are involved by proxy. The Literature Review identified that the presence of service users or carers in meetings is no guarantee of participation and people can feel intimidated by professionals around them (Linhorst et al., 2002). For this very reason, almost everyone suggests that more than one service user or carer should be present in all such meetings or groups, and the VbC report suggests three to avoid potential isolation and stigma. The VbC report also points out that service users and carers are themselves separate groups and need to be treated as such, as their needs and priorities are frequently different.

Presence:

- 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

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

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, but 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/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. For involvement to be accessible to a wide range of service users and carers with different skills, abilities and preferences, a range of different involvement methods needs to be made available. This may mean adopting non-traditional approaches such as creative or outreach activities or working with mediators from diverse communities. Involvement should not have to replicate, or fit in with, a conventional working environment. Many of the reports recommend that a range of ways for people to become involved be made available, in order to make involvement accessible to a wider diversity of service users and carers. All too often, the meeting is regarded as the sole unit of involvement; this is neither adequate nor effective, as many people find meetings difficult to participate in on an equal basis and it often relies on people turning up to take part in a pre-existing group.

'Involvement is not a one size fits all - neither is the type of support people need.'

There are many recommendations and suggested guidelines for making the process of involvement accessible and effective for service users and carers (as well as for the professionals/services). One such example is the Making a Real Difference (MARD) Guidelines (NIMHE/CSIP 2006). Due to the large number of different items included in the process of involvement, we have grouped them under a series of 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 posts;

- 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.

> *I'm speaking as somebody who has personally benefitted very much from service user involvement but I don't think it has made the slightest bit of difference in terms of any service.*

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 people involved needs to consider:
  - Administrative support,
  - Supervision, and
  - Emotional support (the emotional content and cost of involvement should not be overlooked)
- Opportunities for peer support or peer mentoring should be provided;
- 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 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 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;
- Respite care and childcare 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)

For involvement to be meaningful, it has to 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 impact on the people who are involved (for example, increased skills and confidence). However, the purpose of involvement should always remain at the centre of any attempt to assess impact.

'I'm speaking as somebody who has personally benefitted very much from service user involvement but I don't think it has made the slightest bit of difference in terms of any service. Maybe one or two practitioners have thought a bit differently. But then user involvement becomes more a therapeutic intervention than being about what we can change.' (Quotation from DTOOTs, Page 36)

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 culture of the organisation, to the recovery or wellbeing of individuals?

Impact needs to be explored in the following areas:

- Ethos/culture: has the involvement of service users and/or carers influenced the ethos and values of the organisation, project or programme: made it more acceptable and accessible to services and people locally? … made it more inclusive of diverse and marginalised groups?

- Policy and Planning: has the involvement of service users and/or carers influenced the development of policy or the planning of the project (at governance level)? Is it possible to pinpoint specific decisions or directions taken by the programme that were influenced by service users and/or carers? Have specific developments been designed or led exclusively by service users or carers?

- Delivery: has the delivery of the project been influenced by service users or carers? Have service users or carers been involved in delivering alongside other team members (e.g. training, presentations at conferences)?

- Outcomes and outputs: have the outcomes of the programme been influenced by service users or carers? Has the programme as a whole had a different impact than it might have done as a result of the involvement of service users and/or carers? Have any of the materials produced been designed or contributed to by service users or carers?

- Diversity and equality of opportunity: Have people from diverse communities been involved in the activity? How did they experience the process?

Consider carrying out an equalities impact assessment.

- The experience of the service: has involvement made a difference to the experience of the service from the point of view of service users and carers? Regular surveys and in-depth interviews/focus groups to explore the service experience need to be built in to the quality cycle.

- A cyclical approach: Involvement should be regarded as a continuous process and follow a cycle of improvement or development. Some people may use the terminology: Plan – Do – Study – Act (PDSA) often used in health improvement technologies. ●

Find out

Make a plan

Make things happen

Watch and listen

Think and discuss

Change your plan

4: Where Involvement Happens

In order to explore the evidence for service user and carer involvement in mental health services, we have used the following areas or domains for involvement:

A: Individual care and treatment

B: Community involvement

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

D: Strategic (commissioning and development, policy, governance)

E: Monitoring and evaluation

However, we realise that involvement often does not take place within discrete arenas like this: it can and often does develop organically and extend beyond structural boundaries. However, using these domains makes it easier for us to organise the information that we have gathered. In this chapter, we address these areas one at a time, in each case looking at:

• the research evidence for the benefits of involvement,

• the evidence and knowledge surrounding good practice, and

• a summary of the guidelines and tools available for supporting involvement in each.

A: Individual care and treatment

'You put people on wards and then take away the only things that have meaning for them. So it was put into my care package that I was allowed to take my blades on the ward with me, though they were locked up. It couldn't have happened ten to fifteen years ago' (Participant in the NIP Consultations)

Despite the fundamental importance of being involved in your own care and treatment, neither the Literature Review nor the Review of Resources found a great deal of evidence about involvement at this level. Involvement tends to be thought of as something that takes place primarily at an operational or strategic level, rather than as a day to day part of how professionals relate to service users or enabling

people to take more control over their lives and care. Involvement should both start and end at the level of the individual; the mental health and wellbeing of the individual and their experience of services should be at the centre of any involvement strategy. The fact that the Mental Health Act (1983/2007) militates against this at times makes it all the more important that we seek to strengthen people's involvement in their own care and treatment.

1) The benefits of involvement in individual care

Three key issues emerge from the literature about service user involvement in individual care: agreed purpose, choice and control. In other words, the greatest benefits from involvement in individual care and treatment are to be found when you agree with the purpose of your care and treatment, have some choice about it and some degree of control over it. Involvement in individual treatment planning has been linked to improved self-esteem and increased service satisfaction (Linhorst et al., 2002). One study (Lawn et al., 2007) found a reduction in hospital admissions for people engaged in self-management; both Lawn (2007) and Crepaz-Keay and Cyhlarova, 2012, found that self-management has an important role to play in involving people in their own care. Self-help has been found to be useful and empowering (Segal et al, 1993).

2) Good practice in involvement in individual care

For involvement in individual treatment planning to make a difference, it is important that the individual is involved in setting their own treatment goals (Kilian et al., 2003, Linhorst et al., 2002). Similarly, it is not sufficient that people feel involved in the services they receive, but that they believe the services themselves are actually useful (Crane-Ross et al., 2000; 2006). Braye and Preston-Shoot (1993) explored the power relationships between service users and professionals with a view to providing frameworks for empowering service provision. They identified ways in which practice can develop to work with people with mental health problems in an empowering way.

All we ask is that services always ask of each individual: "What is most important to you and how might we achieve that with you?"

These include: reaching beyond labels, symptoms and deficits to wider models suggesting a focus on real life goals; and facilitating access to people outside the professional system whilst recognising its limits.

A recent User-led Study of Service Users' Experience of Recovery Under the Care Programme Approach (Gould, 2013) found that participants emphasised the value of involvement, influence and control for their recovery, but that their experience of this in practice varied considerably. Often it was the attitudes of staff that affected this; some service users had experienced prejudice from professionals and some found it difficult to disagree with the views of professionals, whether because discussions were too 'top-down' or because they feared retribution.

'Some service users I've spoken to, they don't want to go to CPA meetings and some of them even said to me: 'It's not for us, it's for the health professionals, because they're going to do what they want to anyway' [service user quoted in Gould, 2013 p53]

Talking about involvement in treatment goals or an agreed purpose for treatment can be another way of referring to treatment outcomes. It is vital that service users are involved in defining their own outcomes for involvement in individual care and treatment to be meaningful. Outcomes are important at the individual level but are also significant at the operational and strategic levels. The ROLE Network (Relating Outcomes to Lived Experience, a service user network based in the North West) reviewed a number of commonly used outcome measures from a service user

perspective and concluded that an approach based on capabilities may encourage a holistic view and be less excluding.

'Acknowledging that choice is empowering, and control itself is a determinant of wellbeing, the report clearly states outcomes must be selected by service users and carers, and concludes: All we ask is that services always ask of each individual: "What is most important to you and how might we achieve that with you" (Findlater, 2008)' (ROLE Network CIC, 2010)

In relation to control, some approaches to involvement seek to enable people to take greater control of their symptoms (Stromwall and Hurdle, 2003), whereas more advanced approaches seek to enable people to take control of their lives, as in contemporary self-management approaches. Self-management is an approach where the aim is to shift the locus of control from clinician to patient/service user. Some self-management approaches have been developed for specific psychiatric diagnoses, using psycho-education with a leaning towards condition/symptom management (Bauer and McBride, 1996), whilst others have taken a whole life approach (Crepaz-Keay and Cyhlarova, 2012).

Choice is fundamental in involvement at the individual level and ranges from informed consent (a yes or no choice), being given options, through shared decision making (see Perestelo-Perez et al., 2011, Tee et al., 2007, Harris et al., 2009) to independent informed choice; each of which represents a greater degree of involvement than its predecessor. Tee et al (2007) found that greater participation in decision-making was facilitated by a respectful culture which recognised service users' 'expertise' and communicated belief in individual potential.

It has been suggested that signposting alternative sources of support rather than providing them can offer people greater responsibility and choice (Braye and Preston-Shoot, 1993), although this does bring into question the quality of the information and the availability of alternatives to choose from. For Beresford (2013), advocacy can be a key means for supporting service users to become involved,

particularly for people who are disempowered and isolated. However, he points out that it is generally in short supply and not prioritised by policy-makers or services.

Crisis cards, advance directives and other similar tools can offer people the opportunity to make decisions for a time when their capacity may be impaired, thus increasing the chances of their views being considered and reducing the need for compulsion (Swanson et al., 2008). Despite the early enthusiasm for advance directives, there is not a great deal of evidence for their effectiveness, partly due to the fact that they do not have formal legal status and the Mental Health Act can overrule them. A Cochrane review of their effectiveness concluded that there was insufficient evidence that they make a difference (Campbell and Kisely, 2010).

However, Amering et al (2005), in a qualitative study with 33 people, suggested that advance directives can introduce to service users the prospect of being treated as a responsible agent in future interactions with the mental health system. They concluded that they are best seen as 'complex planning tools' rather than as interventions in their own right. Swanson et al (2008) found that completion of an advance directive was associated with lower chances of coercive crisis interventions. Sidley (2012) suggests that, in order to make advance directives (or advance decisions) work in practice, services need to provide staff training, simplify the paperwork and give patients practical support. He gives the example of a fairly simple document produced by Greater Manchester West Mental Health NHS Foundation Trust, which can be scanned into their electronic records system along with an alert that the person has made an advance decision.

Personalisation and personal budgets are another potential means of offering people choice and control; however, it appears that they can offer more than they realise. The evaluation of the national pilot programme indicated that personal health budgets 'had a significant positive impact on care-related quality of life, psychological wellbeing and subjective wellbeing' (Forder et al, 2012). However, Mind's research (Mind, 2013a) identified considerable

concerns among service users about such issues as: widening inequalities, threats to services for people who don't want a budget and paternalistic attitudes/a risk averse culture in the NHS. They also refer to the experience of personal budgets in social care, in which the low uptake among people with mental health problems was put down to very similar barriers, such as a risk-averse culture, fears about losing group services and poor access to good information about how to manage a personal budget. A particular issue identified by Mind is the risk of further marginalising the needs of BME service users, who already experience less choice and access to, for example, psychological therapies at the primary care level. Nevertheless, the research confirmed that there is some potential for personal budgets to become a route for people to gain greater choice and control, to benefit from a focus on health outcomes rather than services and to participate in shared decision-making with professionals.

3) Tools and guidelines that support involvement at the individual level

In recent years there has been a greater emphasis on outcomes from service users and carers as well as from mental health services. This perhaps reflects the move towards Recovery (which tends to focus on the individual's chosen goals) and recovery focused services, but also a tighter focus from providers on measurement and evaluation.

Over the years, service users and survivors have developed a number of tools and methods to address this and to empower individuals to have a greater say in their own care, including advocacy (with a focus on self-advocacy), crisis cards/crisis plans and advance directives. A brief search of the internet found that a number of NHS Trusts have developed guidelines and documentation for enabling service users to complete advance directives. We found examples produced by the East London NHS Foundation Trust, South Essex Partnership NHS Foundation Trust and Kent NHS Trust with Medway Council and Kent County Council Social Services (www.kentandmedway. nhs.uk). This last one is also available on the

Canterbury and District Mental Health Forum website (http://canterburymentalhealth.org.uk).

In general, the documents/tools reviewed for the Review of Resources for use at the individual level tend to focus on empowering the individual to voice their needs and priorities to a service historically based on service outputs, a diagnostic framework and designated care pathways. Several of these tools date from the 1990s, a period of considerable growth in user involvement. One such tool is Leader's (1995) Direct Power, originally published by Brixton Community Sanctuary/Mind/Pavilion Publishing. Developed by service users for service users as an empowerment tool, this had sections covering:

• Building your own personal profile;

• Experiences of services you are in contact with

• Self-assessment of needs checklist.

Another product from this period, the Avon Mental Health Measure (1996) was well thought of in its time. Developed with/by service users in the South West, it was used locally and not widely taken up originally. However, it has more recently been developed for use in Scotland, first by the Scottish Schizophrenia Outcomes study (Hunter and Cameron, 2006) and then developed into the My View tool ('Putting my views at the heart of my mental health services and support'; Healthcare Improvement Scotland with Vox Scotland, 2008?). At the time of writing no evidence has been identified about the actual involvement of service users in the development or use of this tool from Vox Scotland.

Another tool from the same period is CUES (Carers' and User's Expectations of Services) developed by and with Rethink Mental Illness (when it was called the National Schizophrenia Fellowship, 2000) with funding from the Department of Health and in partnership with three research organisations: the Royal College of Psychiatrists' research unit, the Royal College of Nursing and the University of East Anglia social work department (Lelliott et al, 2001). The idea was to develop a self-assessment tool for service users to rate their experience across a range of domains that they consider to be important. It

was therefore developed in consultation with service users. The Carers version of CUES (CUES-C) was developed a little later (Lelliott et al, 2003) and has since been used as the basis for development of the Carers Wellbeing and Support (CWS) questionnaire (Quirk et al, 2012).

More recent developments include Talking Points (Cook and Miller, 2012, for the Scottish Government) and the Involvement Triangle (Torbay Toolkit Team, 2006), the latter being based on the Outcomes Star (Triangle Consulting Social Enterprise, 2009/12). The Recovery Star (MacKeith and Burns, 2010a&b), is based on the Outcomes Star and has been used as an individual tool to support and monitor mental health recovery. Dickens et al (2012), working with the Mental Health Providers Forum, suggest that the Recovery Star has potential for use as an outcomes measure.

More recently, there have been a number of reports and guidelines addressing the involvement of carers in recovery. For example, Machin and Repper (2013) provide a framework of key actions that services need to take in order to support the meaningful involvement of carers in recovery practice. These include the need to identify carers (including those who may not think of themselves as 'carers'); tackling stigma and discrimination; understanding the impact of caring; and developing carer peer support.

B: Community Involvement

In the UK, we usually conceive of involvement as being about service user and carer involvement in care and treatment, or in the development and delivery of services. However, an important context for service user and carer involvement is involvement in their (our) own communities, developing community wellbeing and resilience. Capacity-building within self-defining communities is an essential element of, or basis for, involvement and inclusion. If, as service users and carers, we can support each other within our communities, then we are building our capacity as a community with 'social capital' and our capacity to become involved in influencing what we want to influence.

As Kalathil (2008) points out, people with lived experience of mental distress use different words to describe or define their identities, experiences and understandings, whether or not they use services. These definitions may be based on their own ways of defining what constitutes 'mental distress'. Hence, 'user involvement' may not be the framework they use to define what they do, even if it may look like that to others. For many marginalised groups in particular, community involvement may take precedence over involvement in services; indeed, involvement in services is unlikely to happen until or unless people feel themselves to be part of a strong community with which they identify.

1) The benefits of community involvement

Community involvement can help to build the resilience and capacity of communities to support themselves and address the issues that are of greatest concern to them (Kalathil, 2008). It can strengthen the skills, confidence and capacity of members of the community to become involved in influencing local and national services. Community involvement can also serve to bring the issues of importance to a marginalised community to the attention of the wider community and wider society.

"A growing body of evidence shows that when practitioners begin with a focus on what communities have (their assets) as opposed to what they don't have (their needs) a community's efficacy in addressing its own needs increases, as does its capacity to lever in external support. It provides healthy community practitioners with a fresh perspective on building bridges with socially excluded people and marginalised groups." (Foot and Hopkins, 2010)

Developing the mutuality and reciprocity that builds communities produces positive 'social capital', which is associated with the well-being and resilience of individuals as well as of communities (McKenzie, 2006). '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

> *...when practitioners begin with a focus on what communities have as opposed to what they don't have a community's efficacy in addressing its own needs increases, as does its capacity to lever in external support.*

collective attributes of its members and individual health.

Social capital can also be the product of peer support approaches and the campaigning activities of self-help and service user groups in mental health (Faulkner et al, 2013). Indeed, peer support in mental health has been found to have many benefits, both for individuals and for the communities in which it develops. Faulkner and Kalathil (2012), in a consultation commissioned by Together for Mental Wellbeing, explored peer support with a particular focus on marginalised communities. They found that some of the collective benefits of peer support (mutual understanding, shared identity, collective action) are particularly valued by peer support projects working within marginalised groups.

2) Good practice in community involvement

Good practice in community involvement involves the development of trusting relationships and networks to build social capital, but it also, crucially, involves the capacity of communities to address inequalities. Discussing mental health in the global context, Friedli (2009) suggests that resilience of a community is dependent on whether that community promotes the equality of its members. Reviewing the research in this area, Friedli provides a framework for understanding inequalities and working towards equality by looking at community capital at three levels:

- Environmental capital: structural factors and features of the natural and built environment that enhance community capacity for wellbeing;

- Social capital: norms, networks and distribution of resources that enhance community trust, cohesion, influence and co-operation for mutual benefit;

- Emotional and cognitive capital as resources that buffer stress and/or determine outcomes and contribute to individual resilience and capability.

For Kalathil, partnership working with BME groups needs to be based on a commitment to recognise the diversity of work that service users/survivors are doing within their own communities, sustain people's potential, enable independence and build their capacity to be self-reliant. Investing in people, she says, turns the focus away from a person's mental health status to their role in the community. This represents a more holistic way of working to enable change to take place within communities, to sustain those communities for the benefit and resilience of the individuals within them.

'It is really important that service users have support groups, not just involvement groups. People don't just meet together in order to give service providers what they want. It's every bit as important as involvement, making sure that we actually support each other, because very often services don't support us in the way in which we want to be supported.' [Quotation in Kalathil, J. (2008) 'Dancing to Our Own Tunes']

Sollé (2009), in describing communities of refugees and asylum seekers, explored the value of advocacy in working with refugee community organisations. For many of these communities, the priority may be survival and establishing their basic rights (including the right to remain), and it is only through tackling these issues that mental health can be addressed. This form of advocacy includes advocacy for the community, with the aim of creating a dialogue on issues of mental health and engaging with commissioners and provider agencies to develop community-focused services.

Seebohm et al (2005) explored Sharing Voices

(Bradford), which is a community development project working primarily with people from South Asian, African Caribbean and African communities. They describe how the project promotes social inclusion, social capital and community cohesion through the networks, partnerships and 'safe spaces', which enable people to build trusting relationships. The organisation is based on an ethos of self-help and mutual aid. The one recommendation to emerge from this study is that commissioners should promote a model of community development that requires the active involvement of local people in identifying the problems to be addressed and determining the solutions they want.

In an exploratory study for the Community Development Foundation, Seebohm and Gilchrist (2008) describe 'community wellbeing' as 'a situation where communities are thriving, with many connections between individuals, groups, institutions and services, creating a sense of belonging'. They see wellbeing for the individual and the community as interdependent, and identified the following activities and outcomes in relation to community development in a mental health context:

- Establishing trusting relationships: respectful relationships and constructive partnerships between people from diverse community groups,

It is really important that service users have support groups... It's every bit as important as involvement, making sure that we actually support each other...

local organisations and statutory services. Creating connections within communities, community cohesion.

- Facilitating social and economic inclusion: access to local groups, activities, resources, networks and work opportunities (paid and unpaid).

- Promoting participatory democracy: structures, skills and processes for the participation of local people and mental health service users in the planning of public services.

- Promoting mental health: increased awareness of mental well-being and strategies to increase it, including events, opportunities to talk, Mental Health First Aid training.

- Facilitating self determination, self-help, peer support and mutual aid: collective action to create change, community groups, networks and community led resources, including peer support/ mutual aid and social enterprise.

- Increasing learning: opportunities for learning and personal development, including creative expression and developing leadership and democracy within community groups.

- Promoting equality and social justice: equality increased in social, health, economic and political spheres, particularly:

  ○ Reducing the stigma of mental ill-health

  ○ Reducing race inequality in mental health

  ○ Reducing other inequalities, e.g. associated with gender, sexuality, faith.

In a series of case studies covering people with a range of different health and social care experiences, Faulkner (2010) explores the role that user-controlled research can play in empowering marginalised groups to make a difference within and for their communities, in the process drawing the attention of the wider local and research communities to their needs and priorities. Central to these research projects was the establishment of trusting relationships based on a shared identity between the researcher and the researched, enabling the research to reflect the needs of the community.

3) Tools and guidelines for measuring community involvement

Here we feature just a small number of tools or methods developed to assess or develop the capacity, resilience or social capital of communities or their impact on mental wellbeing. Some of these are proxy measurements of community involvement, in that they are really addressing mental wellbeing and may be more relevant to public health initiatives. Seebohm and Gilchrist (2008) found that community development workers wanted guidance, tools and resources to enable them to measure their outcomes in ways that were not invasive or burdensome. They recommend participatory approaches in contrast to statistical monitoring which could leave workers feeling that the most important aspects of their work were missed.

Mind and the Mental Health Foundation published materials on building resilient communities on behalf of the Mental Health Strategic Partnership with funding from the Department of Health (Mind, 2013b). They identify three key factors that affect resilience: activities that promote wellbeing; building social capital and developing psychological coping strategies. One of the materials they produced is a practical guide for community groups and service providers, available on their website at: www.mind.org.uk/publicmentalhealth.

Another approach is ABCD (Asset Based Community Development) which, like other approaches discussed here, is based on the principle of identifying and mobilising individual and community 'assets', rather than focusing on problems or deficits (Foot and Hopkins, 2010). This report ('A Glass Half-Full') offers practitioners and politicians, who want to apply the principles of community-driven development as a means to challenge health inequalities, a set of structured techniques for putting these asset-based principles and values into practice.

A means of assessing social capital is to examine the 'social return on investment' (SROI). SROI is a model and a measurement framework developed by the Community Development Foundation and the New Economics Foundation (NEF) to help organisations to

understand and manage the social, environmental, and economic value of their activities. It takes into account the full range of social benefits to all stakeholders, rather than simply focusing on revenue or cost savings for one stakeholder. SROI enables a ratio of benefits to costs to be calculated. For example, a ratio of 3:1 indicates that an investment of £1 delivers £3 of social value. It values things that matter to communities and attempts to put a value on such things as self-esteem and confidence.

Nef Consulting (2012) carried out a study with Kirklees Council to explore the extent to which fostering social capital activities contributes to positive improvements in well-being for individuals and communities, using the SROI model. Amongst other things, they concluded that, if more small voluntary and community organisations can be encouraged to 'tell their story' and articulate or evidence their own theory of change (without necessarily embarking on a full assessment of SROI), it will put them in a stronger position to:

• Think about developing new services or activities (that grow social capital)

• Build an outcomes based business model to sustain themselves into the future (in the fast changing landscape with personal budgets and reduced grants or funding)

• Put in place more systematic ways to gather this evidence with their stakeholders on a regular basis

• Recognise the full value of what they do. (Wright and Schifferes, 2012)

A measure of community wellbeing and resilience is WARM – The Wellbeing and Resilience Measure (Mguni and Bacon, 2010) developed by the Local Wellbeing Project of The Young Foundation. The idea of this programme was to explore how local government could improve the wellbeing of its citizens. WARM is a framework to measure wellbeing and resilience at a local level and was designed to help local areas and the agencies that work in them understand their own capabilities and needs. It helps identify who is vulnerable, who is not, and why. It aims to support localism, by giving better information to both communities and residents, and agencies

responding to their concerns and aspirations. The authors see the five stages of WARM as an iterative process: to be repeated over time to help identify the extent to which interventions have led to tangible improvements in life satisfaction. The report is available at: http://youngfoundation.org/wp-content/uploads/2012/10/Taking-the-Temperature-of-Local-Communities.pdf

The Mental Wellbeing Impact Assessment toolkit (published by the NMHDU and updated 2011) uses a combination of methods, procedures and tools to assess the potential for a policy, service, programme or project to impact upon the mental well-being of a population. The MWIA theory and practice was developed in partnership with the National Collaborative on Mental Well-being Impact Assessment. The aims of the MWIA toolkit are to:

• Raise awareness and understanding of mental well-being;

• Enable a range of stakeholders to begin to identify the impact a particular policy, service, programme or project may be having on mental well-being;

• Encourage stakeholders to explore ways to maximise potential positive impacts and minimise potential negative ones;

• Enable stakeholders to explore and develop local indicators to monitor and evaluate progress on promoting mental well-being.

It focuses on population groups who may experience health inequalities and social injustice with a particular emphasis on those most at risk of poorer mental well-being. It also makes the link with social determinants. The MWIA toolkit and reports are available on the HIA gateway - www.apho.org.uk/default.aspx?RID=70494

C: Operational (Services, Projects, Training and Education)

The most well developed area of service user involvement is involvement at the operational level, in the day to day running of services and in the training and education of staff. This is reflected in the volume

and breadth of literature covering this subject; there remains, however, a significant imbalance between the volume of literature produced by academics and professionals compared to that produced by people who have used services or their friends, carers and family members.

'We met the architects of mental health units and had influence on colours, furniture, en suite rooms and size of staff room. We also facilitated debate on single sex accommodation and got the design changed' (Participant in the NIP Consultations)

1) The benefits of involvement at the operational level

The literature review identified a range of potential benefits of involvement at the operational level, including enhanced quality of care (Salzer, 1997, Minett, 2002), improved quality of life (Thornicroft and Tansella, 2005, Peter, 2003, Truman and Raine, 2002), reduction of compulsory admissions (Thornicroft and Tansella, 2005), improved relationships between staff and service users (Lea, 2006), and improved outcomes for service users, as well as some provider outcomes (Thornicroft and Tansella, 2005, Peter, 2003, Minett, 2002, Salzer, 1997).

Benefits have also been identified in relation to service user and carer involvement in training and education. Services have been enhanced by training that is more grounded in the real world and reflects the experiences of service users (Basset and Evans, 2009, Bailey, 2005) and balances what may otherwise be a predominantly biochemical approach (Rush, 2008). Practitioners who have been trained by service users take a more individualised approach to care planning (Wood and Wilson-Barnett, 1999), have taken practical ideas from training sessions and applied them in the service settings (Rush, 2008). Overall though, there is little evidence that existing mechanisms for involving service users in training and education lead directly to improvements in mental health services, and more needs to be done to ensure that service providers, training providers and service users work together with a clear purpose in mind (Repper and Breeze, 2007).

Peer support is a particular means of service users being involved in service delivery. A relatively recent literature review of peer support (Repper and Carter, 2011) suggests that peer support promotes hope and belief in recovery, and improves self-esteem and self-management. Peer support has been used to improve the effectiveness of self-management (Crepaz-Keay and Cyhlarova, 2012). Some studies have shown that peer support reduces inpatient bed use (Lawn et al., 2008, Forchuk et al., 2007) and improves people's physical health (Bates et al., 2008, Cook et al., 2009).

2) Good practice in involvement at the operational level

Research tells us something about what makes for good involvement in services. For example, the Centre for Mental Health (then the Sainsbury Centre for Mental Health) Acute Solutions project (The Sainsbury Centre for Mental Health, 2006; Lea, 2006) identified six ways of supporting effective involvement:

- Equality of inclusion,
- Provide opportunities to meet and be trained together,
- Offer support and consider access issues,
- Help prepare people for meetings,
- Provide speaking opportunities, and
- Provide peer support.

One of the tenets of good involvement is to ensure that a diversity of people are involved; both experience and research tells us that a range of methods is needed to achieve this (Boeltzig et al., 2008, Perkins and Goddard, 2004, Rutter et al., 2004). Different people prefer to get involved in different ways and the methods chosen are likely to have an impact on who gets involved. The NIP consultations found that, for some groups, more creative formats are more likely to get them involved.

Much of the literature has focused on people's attendance at meetings as a means of involvement, but a number of studies have looked beyond this.

• We met the architects of mental health units and had influence on colours, furniture, en suite rooms and size of staff room. We also facilitated debate on single sex accommodation and got the design changed. •

One study with a focus on involving women in developing mental health services (Barnes et al., 2006) identified a range of different mechanisms that engaged people more effectively than conventional planning groups. Game based approaches have the potential to engage people who have otherwise shown no interest in complex consultation issues (Fitzgerald et al., 2011) and Forum Theatre approaches also involve some people who have felt excluded by conventional meeting structures (McClimens and Scott, 2007).

Within meeting structures, there are approaches that help to encourage more equal participation in meetings, for example Nominal Group Technique (Perry and Linsley, 2006, Sloan, 1999), and Delphi techniques (Perry and Gilbody, 2009, Langlands et al., 2008, Fiander and Burns, 2000).

3) Tools and guidelines that support involvement at the operational level

Involvement in services and other activities such as training, education and research, has given rise to by far the largest number of guidelines, standards and tools identified by this search. This is perhaps not surprising as there has been a raft of policy guidance to support service user and carer involvement in services over the years in order to enhance the accountability of public services and organisations, and increase what is sometimes referred to as the 'consumer' voice. In addition, service users and carers tend to be highly motivated to change and improve services, to redress the balance of power that is most immediate to them and to 'make a difference' for those who come after them as well as for themselves.

Due to the number of tools and guidelines identified for involvement in services, projects and other operational activities, they are reviewed in full in the Review of Resources (Faulkner, 2013); here we give just a few examples.

One set of guidelines is the MARD Good Practice Guidelines (NIMHE South West, 2006). It gives a set of key principles with guidance points under each:

• 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

Wallcraft and Bryant (2003), in a policy paper based on the On Our Own Terms survey of mental health service user groups, recommend the production of national good practice guidelines for user involvement based on ten criteria:

1. Making user involvement the norm.

2. Providing a base of support and accountability.

3. Examining and dealing with power imbalances.

4. Professionals should reach out and visit service user groups more often rather than expecting service users to go to professionals' meetings.

5. Enabling service users/survivors to make their own decisions about involvement.

6. Valuing the skills of service users/survivors and helping them gain new skills and confidence.

7. Providing financial compensation for service user/survivor services.

8. Providing user involvement training for professionals.

9. Distinguishing between the needs of users and carers.

10. Ensuring the development of effective user involvement policies for NHS trusts and Regional Development Centres, together with programmes for acting on the outcomes of involvement.

In relation to recovery there is DREEM (Developing Recovery Enhancing Environments Measure), a measure designed to assess a service or organisation's commitment to recovery (see, for example, Dinniss et al, 2007). It can be used as an assessment or organisational self-study, or as an aspect of on-going service evaluation and service improvement efforts. It was designed to be answered by people with mental health problems, who have extensive involvement with the mental health system and are subject to the Care Programme Approach (CPA). There is further information and a guide to using DREEM on the Recovery Devon website (www. recoverydevon.co.uk).

Although some of the guidelines or documents include carers and family members alongside service users, many are specific to service users and user involvement. There are just a few identified as addressing the needs of carers[5]. The National Black Carers and Carers' Workers Network (NBCCWN) produced a good practice guide for people working with black carers: 'We Care Too' in 2002. This guide sets out standards for working well with black carers across health and social care under three headings: assessment, respite and communication and information. In 2008, NBCCWN produced 'Beyond We Care: Putting Black Carers in the Picture.' Based on extensive consultations and a review of existing evidence (including the 'We Care Too' document, above) in the context of the development of a new national carers strategy, this document consolidates the experiences of black carers and carer support services in relation to the needs of BME communities.

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5. These will be added to as the documents in this series are developed.

D: Strategic – governance, commissioning, policy

Service user and carer involvement in the future of mental health services has been national policy in the UK since the 1990 NHS and Community Care Act. There are a number of reasons for the support of involvement at a strategic level: Governments have increasingly wanted services to have a stronger focus on their 'customers' in the way commercial providers of day to day goods and services are, with the aim of leading to more effective, efficient and responsive services.

Service user and carer involvement in the governance of organisations is increasingly common: as trustees on the boards of voluntary sector organisations and as non-executive directors of NHS Trusts. Service users sit on the board of such organisations as the Care Quality Commission and the Social Care Institute for Excellence.

1) The benefits of involvement at the strategic level

For involvement at the strategic level to be effective, the purpose of services themselves needs to be considered. For example, Rummery (2009) showed that for 'partnership working' to be effective, service users must be involved in defining outcomes; i.e. not just 'are services doing things well?', but just as importantly, 'are they doing the right thing?'. This links back to the importance of having shared purpose or user-defined outcomes at the level of individual care and treatment.

Crawford (2002) carried out a systematic review seeking to identify the impact of service user involvement on the planning and development of healthcare. He identified 40 different involvement initiatives with the following benefits:

• Improved self-esteem for the service users involved;

• Improved production of sources of information for patients/service users;

• Improved access to services for patients/service users;

• Examples of completely new services, or closure of existing ones; and

- Other effects on decision-making processes and staff attitudes and behaviour.

One detailed case study of two Mental Health Trusts in London (Rutter, 2004) explored service user involvement from the perspectives of staff, managers and service users. This identified a range of views including some consensus that it could lead to service improvement, but some considered it an extra burden on their time. Overall the study concluded that there was a need to make decision-making processes more open and accessible.

It has been suggested that service user involvement in commissioning services is essential as part of improving the commissioning process (Forrest, 2005), but service user experience of involvement in commissioning is varied and many barriers still exist (Yiannoullou, 2009). The VbC report suggests a range of benefits that might result from values-based commissioning (commissioning that includes the views of service users and carers) in the interests of ensuring that services as a whole more closely reflect the views and priorities of service users and carers.

2) Good practice in involvement at the strategic level

Many of the factors identified as good practice at the operational level also apply at the strategic level, particularly when it comes to participation in meetings and where decision-making processes (and the limits of influence) need to be made open and transparent. Other issues that emerge from the VbC report include: the need for practical and emotional support; to have more than one service user/carer on panels or boards; and the need for training for commissioning roles.

The VbC report also points to the central issue of power and power-sharing between commissioners and service users/carers, and the need for 'a significant shift in culture' (p7). The findings of this report also highlight the need for a greater number and diversity of service users to be involved at all levels of decision-making in the commissioning process. The report recommends that Clinical Commissioning Groups (CCGs) set up a values-based

commissioning infrastructure where possible and develop ways to collaborate with service users as equal partners.

A review of the Clinical Governance Support Team (formed to support development of the best possible clinical governance across the NHS in England) concluded that patient and carer involvement at all levels of an organisation is essential for effective clinical governance (Stanton, 2006).

At a national level, NSUN has worked to establish places on boards such as the Ministerial Advisory Group on Mental Health Strategy, the Joint Commissioning Panel , and the Strategic Partner Programme . In many cases, NSUN has had to lobby to be recognised as a credible organisation that voices the views of service users, alongside larger voluntary sector organisations that can often only represent service user and carer views by proxy.

Involvement at strategic and governance levels tends to involve attendance at meetings, and so all of the good practice factors that apply to meetings apply here. Indeed, the higher the level of meeting, arguably, the greater the need to consider issues of inclusivity and access, support, training, timely information, and the explanation of jargon.

3) Tools and guidelines to support involvement at the strategic level

Although there are not many documents identified for use at the strategic level, several of them appear very useful. All are aimed at commissioners or were developed as a result of working with commissioners. A couple of them use a version of the ladder of participation. The most recent is a web-based tool – the Engagement Cycle developed by the NHS Institute for Innovation and Improvement, the Department of Health and Inhealth Associates (2012). However, a much earlier one, developed by Leeds Health Action Zone in 2001, also appears to have a useful structure. It uses an Involvement Matrix for commissioners to describe involvement in work activities, with five levels of participation against three commissioning categories: Planning, Implementing and Monitoring.

There is a blank matrix for people using the guide to photocopy for their own use.

The Welsh mental health strategy document 'Stronger in Partnership 2' also looks useful (Wales Assembly Government, 2008). It uses three levels: Planning and delivery of services; Care Planning (interesting as it looks at individual care planning, the CPA and Carers); and Evaluation and Learning. It includes a Charter for Service User and Carer Participation and a checklist and monitoring tool. Also in Wales, the Mental Health Measure was passed in law in 2010 and forms part of the current Wales Mental Health Strategy 'Together for Mental Health - A Mental Health and Wellbeing Strategy for Wales'. Developed in collaboration with service users and carers, the aim of the Measure is to ensure that support is available for people with mental health problems, focused on individual needs.

The Outcomes and Commissioning Project developed in partnership between Bradford and Airedale Teaching PCT and the University of Central Lancashire (Bhat et al, 2009) aimed to improve mental health services for local BME communities by enabling them to work together with service commissioners. Using a cyclical approach, members drew up a strategy which aimed to enable the full involvement of BME communities in designing and improving services building their confidence through training and providing on-going support.

Finally the Commissioning Support Programme has developed a useful tool on user involvement and consultation for people with speech, language and communication needs; it presents tables as examples for filling in, once again based on an adapted version of the participation 'ladder' (Commissioning Support Programme, 2011). Although not a mental health specific tool, this one is included for its good design and layout as a toolkit.

E: Monitoring and Evaluation

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.

Reports and guidelines addressing the evaluation or monitoring of involvement identified by the Review of Resources were few in number but varied in nature. Two reports are useful for reading about the reasoning behind evaluating involvement: the SCIE Participation Guide 20 (SCIE, 2007) and a 'think-piece' produced by the Shared Learning Group from voluntary organisations interested in involvement. The SCIE Participation Guide came up with nine 'big questions' and a list of 20 pointers to help in the evaluation of service user and carer participation.

At the individual level, there is the 'Involvometer' designed by Premila Trivedi (2003) for an individual or group to use after being involved in something, to enable them to evaluate it retrospectively. The Involvometer was used by Jerry Tew et al (2004) in their good practice guide to involving service users and carers in mental health training and education. Their report is worth looking at if this approach to monitoring is of interest, as they developed a number of tools to enable reflection on involvement for staff, students and service users/carers.

The tools developed for the Priory Group by Together for Mental Wellbeing and the Mental Health Foundation (2011/12), for assessing individuals' involvement in their own care, are also worth considering here. They are accessible and 'user-friendly', and designed for different groups of people: people in forensic services, children and young people, general and people with learning disabilities.

Other useful tools include the MARD products. 'Monitoring and evaluating service user and carer involvement' developed by NIMHE North West (2007) is highly thought of and was developed by and with service users and carers. It proposes a range of different ways for evaluating involvement and includes an 'end of involvement' questionnaire. Similarly the Involvement Passport (NIMHE North West, 2006) is a good example of an approach for enabling service users and carers to take their involvement history with them into new opportunities.

All of these still struggle with evaluating or monitoring the outcomes of involvement. Even the SCIE Participation Guide on evaluation (SCIE, 2007) focuses primarily on process. Indeed, they point out that there is a gap between the participation of service users and carers (where there is considerable activity) and any systematic evaluation of what difference this is making.

Recent attempts to investigate the impact of involvement on research have been undertaken by the organisation INVOLVE which commissioned the report' Exploring Impact' by Kristina Staley (2010). The fact that it has not routinely been attempted may in part be due to the ethical argument about involvement – that it is a good and right thing to do in and of itself. However, this argument risks tokenism and does not take into account the powerful motivation behind involvement - that we want our involvement to make a difference.

Evaluating the process alongside the activity or retrospectively can be easier than assessing the outcomes of involvement. For the MARD product on monitoring and evaluation (NIMHE North West, 2007) and others, it is important that the intended outcomes are laid out from the start in order to be able to reflect on them at the end. The National Continuous Quality Improvement Tool for Mental Health Education (Brooker and Curran, 2005; 2006) is useful here. It takes into account the development, delivery and evaluation of programmes, and has a strong emphasis on the involvement of service users and carers in design and development, delivery and evaluation of mental health education programmes. It is a practical tool for evaluating quality and is intended for use by a group ideally comprising representation from all local stakeholders. It takes a cyclical approach to continuous improvement, which may be the most practical way of looking at outcomes in what is essentially a process of co-production.

One method that has a great deal to contribute to this discussion is user-focused monitoring (UFM), a process that originated at the Centre for Mental Health under Diana Rose, for the monitoring of services (Rose, 2001; Kotecha, 2003; 2007). It started from the premise that, if the evaluation of services

was to reflect the concerns and views of the people who use them rather than those of providers, then service users should lead the process at every stage: from the questions asked, through the collection, analysis and interpretation of data to the final reporting of the results and development of recommendations for change. UFM has been used to influence service development and also to identify different perspectives from traditional service monitoring. The potential benefits of carrying out User-Focused Monitoring (Kotecha, 2003) include:

- providing an opportunity for people to lead and carry out an evaluation of a mental health service (drawing on their personal experience of services);

- enabling the voices of marginalised service users to be heard and to influence service development;

- providing new perspectives and information to service providers;

- providing a crucial 'tool' for clinical governance;

- actively enabling the development of equitable and constructive working partnerships between people who use services, service providers and commissioners and wider communities within a locality.

Many reports propose a cyclical approach to involvement and its evaluation, emphasising that it should be a continuous process open to improvement, rather than a one-off exercise. Mind uses the RESPECT cycle: recruitment – expectations – support – plan – evaluate – time to feedback. Others propose a more modified version of the 'Plan Do Study Act' cycle often adopted by health improvement programmes (see, for example, The Institute for Healthcare Improvement: www.ihi.org/knowledge/Pages/HowtoImprove/default.aspx). The User-Focused Monitoring Guide (Kotecha, 2003; 2007), developed at the Centre for Mental Health, also suggests a cyclical approach to monitoring services. ●

5: Overarching Themes

A reading of the reports listed in the introduction, and of the many reports and articles they refer to, has given rise to a number of overarching themes about the theory and practice of involvement. These themes have informed the revision of the standards and are explored further in this chapter under the following headings:

- **Power**
- **Diversity and equality**
- **Principles and values**
- **Commitment to change**
- **Barriers and challenges**

Power

Any discussion about involvement that has the aim of influencing and bringing about change inevitably leads to a debate about power and where power is located. Many of the reports tell us that it is important for power differentials and how they impact upon involvement to be acknowledged at the start of an involvement process. This is a part of the principle of transparency, which enables people who are coming together to develop a foundation of trust. Decision-making processes need to be made transparent from the start in order that people know where the power lies, and time needs to be taken to think through how the involvement process will deal with tensions and disagreements (Blakey, 2005).

Power is inherent in a mental health system that can detain and treat people against their will, but it is also experienced differently by different groups of people. A sense of powerlessness can prevent people from getting involved or wanting to get involved. People held in forensic services have little power over their day-to-day lives and even less over the bigger decisions made about service development and policy. People with learning difficulties and mental health problems also tend to be marginalised within services and within involvement settings, as identified in the WISH Report. Some BME service users, especially those from African-Caribbean and African communities, are over-represented within mental health services, often at the harshest end of services, but are under-

I suppose there's that underlying thing about power in that, yes we can say what we like, but at the end of the day, they are going to make the decisions...

represented when it comes to user involvement (Trivedi, 2009). Trivedi (2009) highlights the need to recognise and address the impact of personal and institutional racism, and to explore the role and power relations between service users and mental health professionals in 'user involvement' settings.

The VbC report discusses power in the context of discussing the potential co-production of services. Genuine co-production would mean a culture shift in services; if service users are to be equal partners in the commissioning of services, they would also need to share in the responsibility and accountability for those services. Some of the service users consulted for the report did not feel that this was realistic. Equally, some were pessimistic about the potential for clinicians and commissioners to share their power sufficiently to allow for service users to make a difference.

'I suppose there's that underlying thing about power in that, yes, we can say what we like, but at the end of the day, they are going to make those decisions. The people who've got the purse strings.' (Service user quoted in the VbC report)

Many of the documents identified by the Review of Resources refer to a version of Arnstein's 'ladder of participation' (Arnstein, 1969) which is based on eight rungs or levels of citizenship and power. There have been many adaptations made to make the ladder of participation more relevant to health and social care services, and to mental health services in particular. There are also criticisms of it as a single dimension based solely on power (Tritter and McCallum, 2006). For Begum (2006), different levels of participation

are valid for different groups of service users (or others) and at different stages of policy and service development; the single dimension suggested by Arnstein's ladder does not allow for this. It is not enough on its own (or we would not now be looking at other dimensions such as the how and the why and the impact of involvement), but power, and the sharing of power, is still central to considerations of involvement. A ladder of participation still retains some validity in describing the level of power achieved within a particular organisation or activity.

Tew et al (2004), in discussing service user and carer involvement in mental health education and training, use a ladder with five rungs: from no involvement up to partnership. For others, partnership is not high enough to be top of the ladder. Another version of the Involvement Ladder was developed by Susan Lawrence (and adapted from the National Youth Agency's Hear By Right materials, NYA 2008). These seven rungs or levels run from informing up to initiating. Mind's Engagement Toolkit uses four levels, which similarly culminate in user-led initiatives:

1. 1st stage consultation, questionnaires and e-campaigning

2. In depth consultation, participants can express views outside of fixed questions

3. Deciding and/or acting together, in partnership

4. Encouraging/providing a platform for initiatives led by people with personal experience

The significance of the use of ladders of participation is to enable some assessment of the level to which involvement has penetrated an organisation, and therefore the power that has been gained or shared. A ladder can also be used to monitor the presence of service users and carers within an organisation's hierarchical structure: how many and who are present at what level. Several documents suggest that it is vital for involvement to reach the top levels of power, to influence the governance and decision-making of an organisation, if it is to make a real difference. Equally, there are others that suggest that involvement has little meaning unless it has influenced the level of individual care such that

people feel that they have a say over their own care and their own daily lives (for example, the Waltham Forest Charter, 2004).

Diversity and equality

Social inequalities, and the associated prejudices and discriminatory behaviour can be played out within service user and carer involvement groups and activities just as easily as anywhere else. Principles of equality and diversity need to be extended to all minority and marginalised groups, particularly those subject to greater stigma and discrimination within the mental health system.

There are a number of reports and guidelines that specifically address diversity and equality in involvement and others that include mention of diversity and emphasise its role and importance in the overall process of involving service users and carers, the aim being to ensure that involvement actively includes people from marginalised groups. Foremost amongst these is 'Dancing to Our Own Tunes' (Kalathil, 2008/2011), which presents a Charter and Guidelines for working in partnership with BME service users and organisations. The WISH report 'Unlocking Service User Involvement in Forensic Settings' (NSUN/WISH 2011) revealed the parlous state of user involvement in forensic settings generally and for women and people with learning difficulties in particular.

Amongst the reports and guidelines reviewed for this report there are some that address diversity and equality directly, such as: the MARD Minimum Standards for Working with Diverse Groups and Communities (CSIP/NIMHE, 2006); the MARD Ways of Working with Diverse Groups and Communities (CSIP/NIMHE, 2007). The Outcomes and Commissioning Project for Bradford and Airedale 2007-9 (Bhat et al, 2009) presents a useful model for commissioners. Other reports mention diversity and equalities issues as part of an overall framework, for example: the Guide to User Focused Monitoring (Kotecha et al, 2007), The Ethics of Survivor Research (Faulkner, 2004), and Good Practice Guidelines for Involving Service Users and Carers in Clinical Psychology Services (Sheldon and Harris, 2011).

What is clear from reading these is that addressing diversity and equality in involvement is not simply about ensuring the presence of people from diverse communities. It is also about establishing underlying principles, purpose, process and impact; it is a thread that runs throughout all of the 4Pi standards. In order to address diversity we need to adopt principles and values that are meaningful to diverse communities, make efforts to reach out to different groups and use a range of different approaches to engage and involve people.

Underlying values are key to addressing issues of diversity: Kalathil's (2008/2011) guidelines demand a 'genuine commitment from all partners to supporting race equality' and the enclosed charter incorporates two points that address this:

• Acknowledging the discriminatory experiences that people from black and minority ethnic communities face within society, mental health services and within generic user involvement initiatives; and

• Recognising the role of these experiences in making individuals experts in their own right and in informing the nature of partnership working…' (Kalathil, 2008)

Principles and values

It is significant that service users and carers, particularly from BME communities, tend to emphasise the role of underlying values and principles for involvement, where sometimes service or professional-led involvement guidelines focus more on procedures and practicalities (see, for example, Kalathil, 2008 and Faulkner, 2004). There is perhaps good reason for this: as service users and carers, we know that attitudes are at the core of much that takes place in mental health, with the underlying threats of social exclusion and stigma and discrimination. To be meaningful, involvement needs to overcome such barriers and start from a basis of shared values. Furthermore, shared values and principles seek to ensure that the organisational structures enable access to and from marginalised groups and communities, and adopt a respectful approach to all who participate.

Guidelines that set out underlying values or principles include: Dancing to Our Own Tunes (Kalathil, 2008; 2011, the Guide to User Focused Monitoring (Kotecha et al, 2003), the Ethics of Survivor Research (Faulkner, 2004), Tipping Point (Rice and Robson, 2006), Good Practice Guidelines for involvement in clinical psychology services (Sheldon and Harris, 2011), the National Youth Agency's Hear By Right Toolkit for participation of children and young people (NYA, 2008; Badham 2004; Badham and Wade 2005), MARD Minimum Standards & Ways of Working with Diverse Groups and Communities (CSIP/NIMHE, 2006 and 2007), and the MARD Good Practice Guidelines (NIMHE South West, 2006).

Commitment to change

A commitment to change is one of the core principles for meaningful involvement, and is one of the reasons for arguing for clarity and transparency of purpose. Clearly, the purpose of involvement is based on the perceived need to change and improve services, lives or organisations, and so change has to be a vital part of the picture. Service users and carers need to know before they begin if there are limits to their involvement, power and influence. Organisations involving people need to do so with the intention of listening to them, and acting upon their suggestions: enough for their involvement to make a real difference. It is no accident that the CSIP/NIMHE guidelines for involvement were entitled 'Making a Real Difference'.

Where recommendations from service users and carers are not taken up, explanations should be given for why this is so. If an activity is established as a genuine partnership or system of 'co-production', the rules for decision making must be made clear to everyone. In the VbC report, service users and carers highlighted the importance of being able to see evidence of their suggestions being heard and acted upon:

'Make sure that service users' views are acted upon. They're not just listened to but they're actually heard… The services should reflect the needs of service users and carers.'

Make sure that service users' views are acted upon. They're not just listened to but they're actually heard…The services should reflect the needs of service users and carers.'

'If a service user has suggested this, or suggested that, and then you find that everything they say has been blocked…you can see then, they're not really being heard.' (Service users quoted in the VbC report)

Many reports and guidelines refer to the importance of having a 'commitment to change' or 'an openness to change', most of these originating from service users/carers. The Guide to User-Focused Monitoring (Kotecha et al, 2003) is a good example of this. One of the essential criteria for a UFM Project is that there should be a 'clear focus on development and improvement of those services most frequently used by service users…' and 'a commitment to implementing the recommendations'. The two SCIE Guides to Participation (SCIE 2007; 2008) both talk about change; the SCIE Stakeholder Participation Guide 20 (on evaluation) asks organisations to consider what kinds of change they would expect from participation and at what levels in the organisation.

Barriers and challenges

The barriers and challenges to involvement have been described in a number of reports and documents. Some barriers are generic and some apply to particular marginalised groups and communities of service users and carers. For example, the Shaping Our Lives research report 'Beyond the Usual Suspects' (Beresford, 2013) usefully identifies both 'existing exclusions' (equality issues, where people live, communication issues and the nature of impairments) and external barriers to involvement. The barriers listed include: devaluing service users, welcoming some views more than others, tokenism, stigma, confidence and self-esteem, financial barriers, language and culture and inadequate information about involvement. Hitchen et al (2011) identified three key barriers or issues that arose in their reflective study of service user involvement in a participatory action research project: language & jargon, the emotional cost of involvement and power dynamics.

Another issue of particular significance to marginalised groups is that of fear: fear that if you say something critical about a service, this will result in some kind of reprisal. 'Although this fear is not universal, the project's findings suggest that it does seem to be widely experienced among some seldom heard groups and individuals.' (Beresford, 2013: p.9).

Blakey (2005) points to the sense of powerlessness engendered by the health system as a barrier to involvement, as well as the belief that the health service will not listen or change in response to people's views.

'Participants did not feel valued as a source of solutions, so did not feel encouraged to invest time and energy in engaging. This lack of trust came from feelings that non-medical forms of knowledge are not respected, and from the emotional impact of negative experiences as a patient.' (Blakey, 2005; p.4)

One of the barriers to effective involvement is the lack of a shared language with which to discuss it, and a tendency on the part of professionals to use excessive jargon and acronyms. Several people consulted for the VbC report were critical of the use of jargon and acronyms in commissioning, and expressed the need for clear communications in order to be inclusive of service users and carers.

'A lot of the time you go to these meetings and they're coming out with a whole load of acronyms. And people are thinking 'I haven't got a clue what they're talking about'!'

6: Concluding comments

'I think that as far as service users and carers are concerned, language should be made as simple as possible, you know… if you've got a panel, everyone needs to understand what's being discussed.' (Service users quoted in the VbC report)

The aim for a shared language with which to communicate about involvement was an issue for many of the people involved in the NIP consultations. They talked of the need to avoid language felt to be stigmatising by certain groups of people, for example: 'mental illness', or (for some people) 'drug user'.

Language also needs to take into account the fact that some people do not speak English. Again, participants in the NIP consultations talked about this issue and ways of dealing with it. One group reported that a social support organisation called 'developing partners cic' (www.developingpartners. org.uk; a community interest company) in Stockton On Tees was using an evaluation tool designed for people who have difficulty reading and writing, including people whose first language is not English. This tool was designed to make it easier for people whose first language was not English to evaluate the role of developing partners in their recovery journeys by using a drawing of the human body as well as using words.

> *'Some may be fluent in English but I am not confident to speak in public so they need to be prepared beforehand; they should be allowed to write the questions and give it to be read out. Those important subtle things needs to be put into place'.* (Participant in the NIP Consultations) ●

This report has presented the NIP 4Pi national standards for involvement. This has been done within the current policy and practice context for the involvement of both service users and their families, friends and carers. The report has examined a number of areas in which involvement happens and presented some overarching themes. An exploration of these themes reveals that much has been achieved but there is also still a great deal of further progress needed to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of mental health and social care services.

In the 20th Century we saw a movement from non-involvement or disempowered involvement to a position where service users and their families achieved at least the vestiges of meaningful involvement. In the 21st Century we must strive for a position where involvement is the bedrock on which all services are built.

In our many discussions about service user and carer involvement, we came to agree that policies and procedures that enable service users and/or carers to become involved in influencing or delivering services, whether nationally or locally, mean little if they make no difference to individual lives and the everyday experience of using services. The following quotation illustrates the way in which involvement can remain disconnected from the everyday experience of using mental health services.

> *'Last year I ended up in hospital. On the Monday and Tuesday I was training. Everybody was very attentive and respectful and wanted to hear what I had to say. On the Wednesday I got sectioned and by evening I was in the ward where nobody had the slightest interest in what I was saying or what my views were and it was all down to my pathology. And I was suddenly a total non-entity and it was really weird how suddenly you could overnight just change...be treated so differently. People are treated with respect, in terms of user involvement work, but then when they end up in that situation they just become a number.'* (quoted in Kalathil, 2011 p44)

7. Next Steps

I was training. Everybody was very attentive and respectful and wanted to hear what I had to say. On the Wednesday I got sectioned and by evening I was in the ward where nobody had the slightest interest in what I was saying or what my views were ...

Returning to our vision, we want to see effective and meaningful involvement building resilience and changing people's lives; genuine partnership working between mental health services, professionals, service users and carers, based on agreed and shared outcomes; and

a partnership of expertise working towards common goals of respect, recovery, choice and control for each and every individual who comes to use mental health services. ●

Although the current funding ends in March 2015, the NIP team will continue to disseminate the 4Pi standards and build a resource repository accessible to all sharing literature, research, tools, guidance and examples of good practice. The work is being evaluated and the results of this will be made available via the NSUN website. We are collecting case studies to demonstrate where organisations have adopted the 4Pi framework and found it useful. We are also working on developing indicators to form the basis of a self-assessment tool for organisations adopting 4Pi and wishing to improve their involvement practice.

The NIP team will continue to encourage organisations, services and individuals to sign up and use the 4Pi standards, working alongside people within the three pilot sites (Leicester, Hackney in London and Newcastle in the North East) as well as elsewhere, and engaging organisations at a national as well as a local level;

The companion documents to this report will be finalised (the literature reviews and review of resources) and made available to people via the NSUN website, including a new document to be produced on carer involvement;

Over the following year (2015-16), the NIP team plan to carry out a piece of work to map black and minority ethnic mental health service user involvement across England. This will enable us to gain a a clearer picture of the work that is underway in improving community mental health and influencing mental health policy, to document the work of BME groups and organisations, acknowledging achievements, sharing ways of working and start a process of mutual learning and support, and to Identify specific needs for capacity building and leadership development in line with NIP's stated objectives. We shall incorporate the learning into the overall NIP work, creating a theory and practice of user involvement in mental health which truly reflects the diversity of viewpoints and ways of working. ●

8. References

Please note: this is a full list of the references used to compile the accompanying literature reviews to this report listed on page 6: not all of these references appear in this report.

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