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Good Practice Guidelines to support the involvement of Service Users and Carers in Clinical Psychology Services

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Contents

The purpose of the guidelines	1
How the guidelines were developed	2
Part I: The right to be involved	3
National Policy contexts	3
Why involve? The value of service user and carer involvement.....	4
What is meant by ‘involvement’?	5
Who to involve?	6
How: A strategic approach	7
The role of clinical psychologists.....	9
Part II: Starting on the right foot	11
Principles.....	11
Obstacles to negotiate in service user and carer involvement	12
Supporting processes.....	14
The involvement of diverse groups of service users and carers.....	15
Part III: Taking the bull by the horns	20
Starting out.....	20
Methods.....	25
Evaluation.....	29
Conclusions	29
References	31
Appendix A: Service User and Carer Involvement Profiling/Planning Tool	35
Appendix B: Planning Proforma	40

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The purpose of the guidelines

These guidelines are designed to support good practice in service user and carer involvement in the work of clinical psychologists and within clinical psychology services. They could also be used by service users and carers to lobby services for (good practice) service user and carer involvement in local services.

The guidelines are divided into three parts. Part I summarises the current context of involvement by outlining key policy drivers and considering underpinning issues – essentially the why, when, what, who and how. Parts II and III have a more practical focus to inform and support the planning, running and evaluation of involvement initiatives. Part II considers underlying principles and barriers as well as supporting processes and issues relating to the involvement of a diverse range of people with different needs and backgrounds. Part III outlines considerations when initiating involvement activities, including tools for scoping organisational capacity, service-level mapping and planning specific initiatives. Finally, a range of involvement methods and numerous examples are described.

The guidelines are intended to be aspirational, but also to provide a framework within which a locally relevant, genuine involvement culture can prevail.

How the guidelines were developed

The guidelines have been led and developed by service users and carers and, as such, 'live the values' of involvement. The DCP's Service User and Carer Liaison Committee provided oversight of the guidelines development. The primary authors are individuals with direct experience of using mental health services, one of whom brings the dual perspective as a practicing clinical psychologist.

A robust and thorough process was adopted for the production of the guidelines. An initial survey was undertaken to find out what clinical psychologists want from such guidelines and also to identify some current involvement initiatives. A literature review was undertaken which included 'grey' and service user literature. The guidelines were peer-reviewed by service users and carers with expertise in involvement. Individual clinical psychologists from a range of settings were approached to provide feedback on the draft guidelines and case examples. There was also a formal consultation process for which clinical psychologists and service user and carer groups were approached.

Part I: The right to be involved

National Policy contexts

Beyond the moral and democratic impetus to include people in choices about their lives, political drivers in recent years have made a solid case for increasing involvement. The involvement of service users and their carers in commissioning, planning, delivering, researching and evaluating UK health services has been gaining ground as a necessary and increasingly valued enterprise, culminating in a strengthened 'duty to involve' for NHS health care organisations and Strategic Health Authorities which came into force in November 2008.

The Department of Health (e.g. 1999, 2000, 2001) has stipulated that involvement is required at a national and local level. Section 242 of the NHS Act (2006) requires the involvement and consultation of patients and the public in planning the provision of NHS services and decisions about their operation. The NHS Constitution (2009) sets out the right for service users or their representatives to be involved in the planning and development of services and the pledge to reflect the needs and preferences of patients, their families and their carers, to work in partnership with other organisations to benefit and be accountable to patients, local communities and the wider population.

A Stronger Local Voice (DoH, 2006) outlined a framework for the involvement of all users of health services. It focused on effective involvement in commissioning services in flexible and creative ways through building capacity in non-Governmental organisations and disseminating good practice through local involvement networks (LINKs), overview and scrutiny committees and commissioning, and a stronger national voice. LINKs are regional networks comprising of local people and organisations tasked with monitoring and reporting on services in their area (DoH, 2009).

The Mental Health (Care and Treatment) (Scotland) Act 2003 (in effect since April 2005) outlined the right of people experiencing mental health problems in Scotland to be involved in all facets of assessment, care, treatment and support. Both past and present wishes should be considered and sufficient information should be provided in a format suitable to be understood by the individual, to enable full participation.

In Wales, *Stronger in Partnership 2*, published in 2008, supplied guidance to promote involvement (defined as 'to include, to concern and to surround') built on the aim for service users to be 'genuinely and constructively involved in all aspects of mental health services', a principle enshrined in the Welsh Assembly's adult mental health strategy, *Equity, Empowerment, Effectiveness, Efficiency* (2001).

The Health and Social Care Act (2008) outlined that the Care Quality Commission (CQC), the independent regulator of health and social care in England, must decide with service users and carers how it will 'ensure that proper regard is had to the views expressed by service users and carers ... and arrange for any of its functions to be exercised by, or with the assistance of, service users and carers'. To this end, the CQC has published *Voices into Action*, a comprehensive and ambitious involvement strategy.

The creation of Foundation Trusts was part of the Government's plan to decentralise public services and to help create a patient-led NHS. Local residents, patients and staff can become members of a Foundation Trust and influence how the organisation is run. Members are consulted on key local strategic issues and can stand and vote for a Board of Governors.

Involvement and engagement are wider than just health and social care. For example, in March 2009, the Strategy Unit of the Cabinet Office produced a discussion paper called *Co-production in public services: A new partnership with citizens* which gave the following definition of co-production: 'a partnership between citizens and public services to achieve a valued outcome'. World Class Commissioning, launched in 2007, requires commissioners and organisations to 'work with community partners' and 'engage with the public and patients'.

In summary, there is a developing culture, enshrined in law and supported by national policy directives, that requires the active involvement of local communities in the planning and development of services. Users of health and social care services and their carers should expect to be involved, not only in individual care planning, but also in the development, provision and monitoring of services. To this end, individuals and groups can exert leverage by lobbying local services as well as working in partnership with service providers and commissioners to ensure involvement is meaningful, embedded and of a high quality.

Why involve? – The value of service user and carer involvement

The full benefits of involvement are realised through an ongoing relationship that is built up over time, and undertaken in a systematic way, alongside specific initiatives as needed.

Effective service user and carer involvement has an important role in assuring that a service is high quality, accessible, inclusive and meeting the needs of clients and potential clients. When implemented well, it can be invaluable in ensuring that a service is person-centred and responding to need. Full and active involvement of local people and patients is a fundamental to the vision and framework for World Class Commissioning to ensure that the optimal services are commissioned for the local population to improve health outcomes, reduce inequalities and promote well-being.

Active engagement of service users, for example, in the planning, provision or evaluation of services, counteracts feelings of disempowerment and passivity that receiving services can engender and thus aligns itself with recovery-based approaches as well as inclusion and citizenship agendas.

The new registration requirements for all NHS Trusts feature involvement as an essential requirement. Organisations have to be able to demonstrate that they have robust involvement mechanisms in place and that they are working effectively, for example, as part of ongoing monitoring of the quality of care provided. The Care Quality Commission will undertake 'provider compliance assessments' to ensure that NHS Trust registration standards are consistently met. (Care Quality Commission, 2009).

Benefits of co-production are cited as including improved outcomes, active public participation and better value for money. Individual budgets, self-directed support, expert patient programmes and family intervention projects are provided as examples of co-production in practice.

The increasing emphasis on outcomes, rather than on processes or head-counting provides the ideal opportunity to work in partnership with service users and carers to develop outcome measures for services and interventions that are meaningful and relevant to the lives of service users and carers. *Patient Reported Outcome Measures* (DoH, 2008) and *User-Focused Monitoring* (Rose et al., 1998) provide excellent methodologies for eliciting appropriate metrics.

What is meant by ‘involvement’?

Arguably, those who have visited a GP, been in hospital, attended therapy or met with a CPN have all been ‘involved’ (Shepherd et al., 2008). However, service user and carer involvement as described in these guidelines aspires to the relationship between individuals and services to be an equitable, inclusive partnership. Though power differentials and expertise between these three groups (service users, carers and mental health professionals) may vary in differing circumstances, the goal of involvement is for services to learn from the people they work with and to work towards decisions, changes and ‘airtime’ being as user- and carer-led as possible, with mental health professionals utilising their training to provide a service that is ‘on tap not on top’ (Repper & Perkins, 2003).

Involvement and the Recovery movement have many areas of overlap and one may not be achievable without the other. For the purposes of these guidelines, Involvement is intended to refer to principles and approaches that lead to individuals having real choices (both in their treatment and in facilities) and their voices heard and heeded both individually and collectively. ‘Recovery’ here refers to the value placed on service users’ and carers’ own expertise and the importance of them determining their own goals.

Much of the literature conceives of involvement initiatives being stepped, akin to rungs on a ladder (e.g. Tew, Gell & Foster, 2004). Other authors, for example, Stickley (2006), suggest that service users taking power on their own terms (emancipation) is the ultimate aim. Arnstein (1969) amalgamates these positions and emphasises the unhelpfulness of non-participation and ‘token’ gestures. She lists eight different types of participation:

1. Manipulation (individuals asked to ‘rubber stamp’ initiatives through attendance, to suggest their support).
2. Therapy (here determined as people being offered the opportunity to attend groups to discuss their ‘problem’ rather than addressing complaint at the heart of it).
3. Informing (telling people what they are entitled to).
4. Consultation.
5. Placation (including a minority of individuals whose ideas can be easily overruled and who cannot consult those they ‘represent’).
6. Partnership (sharing of responsibilities).
7. Delegated Power (individual service users and/or carers having responsibility for negotiated specific plans).

8. Citizen Control (service users/carers having authority over an institution (such as an NHS Trust) with the ability to negotiate themselves how external bodies might alter their terms of reference).

(Adapted from Arnstein, 1969)

Simpson, House and Barkham (2002) suggest that for successful involvement, key considerations include determining whom or what the activity might affect within and outside the organisation; whom the stakeholders are; how much 'power' they have; and factors that might limit the choice of suitable involvement 'technologies' or mechanisms. Selecting, implementing and evaluating the technology in a reflexive manner may increase the individual's sense of inclusion – which itself should be monitored. They also suggest that service user and carer individuals may require support, such as from dedicated personnel, to get involved successfully.

Who to involve?

An underlying principle of service user involvement is valuing the personal or 'direct experience' of either receiving services or having (mental) health conditions/problems. The issue of who to involve starts at the planning stage of involvement initiative.

Consideration needs to be given to the purpose of the involvement and identification of the group(s) that an initiative is trying to reach. If a health needs assessment is proposed or the development of a local service is under consideration, then wider engagement within the local community may be indicated. On other occasions, the focus may be on involving people who use a particular service, for example, substance misuse, anger management, secure services, or particular sections of the community, for example, young people, older people, parents, BME groups. There will always be 'groups within groups' who may be described variously such as 'harder to reach' and 'less heard' which need to be routinely considered when deciding who to consult whether for a specific initiative or as part of wider engagement (see the section on diverse groups and the building capacity checklist).

Example: Following a consultation with service users, the Mental Health Act Commission decided to particularly focus its involvement work on people with direct experience of detention as most relevant to its remit and so set up a Service User Reference Panel (SURP) of people with current or recent experience of being detained. Specific outreach work was also undertaken, for example, to Asian service users, people with learning disabilities to ensure the SURP had a diverse membership.

When engaging with people, there is a need to be mindful of terminology. The term 'service user' is not wholly accepted with alternatives such as 'consumer', 'patient' and 'survivor' being suggested. Though alternatives are acknowledged, the term 'service user' will be used throughout these guidelines to refer to individuals who have personal experience of using mental health and/or psychology services. The term 'carer' is similarly problematic with many 'carers' seeing their primary role as being a partner, sibling, friend or parent. The term 'carer' will be used throughout these guidelines to refer to people,

often family members, partners and friends, who care for and about people who use or have used mental health services.

Throughout these guidelines and in the planning tool (Appendix A), movement towards decisions and processes being service user- and carer-led is advocated. It is acknowledged that this may not sit comfortably with some highly trained clinical psychologists who wish to make full use of their experience. It is not suggested that clinical psychologists' knowledge and skills are redundant but that service users and carers should make their own decisions, informed by the experience and training of clinical psychologists providing their services, representing a further extension of clinical psychologists' expertise in being 'on tap rather than on top' (Repper & Perkins, 2003). As such service users and carers can collaborate and work in partnership where, even if external constraints are in place, aspiring towards diffusing often pervasive power differences means service users and carers can make decisions on issues that significantly affect their lives.

How: A strategic approach

To ensure that involvement is both integrated and embedded, an organisation's involvement strategy should clearly interface with other organisational strategies, priorities and processes, for example, clinical governance, human resources, Single Equality Schemes, and the corporate plan, as well as with frontline teams and services, for example, through work plans, job descriptions.

The Department of Health has produced statutory guidance – *Real Involvement: Working with people to improve health service* – for NHS organisations to support the implementation of the updated 'duty to involve' with advice about best practice on embedding involvement in organisations.

Most, if not all, organisations have involvement strategies and there are many examples freely available. From a service user and carer perspective, the following aspects of a strategy particularly help establish and support meaningful involvement:

Dedicated resources: The involvement strategy should provide dedicated personnel to build capacity for involvement within the organisation. Whether this is a team or an individual will depend on the organisation. Though dedicated involvement personnel can resource involvement (through capacity building, training and developing relationships with involvement stakeholders), responsibility for developing and implementing local involvement initiatives should rest with the team/service (Figure 1, p.??). Within particular services or teams, resources should be factored in to support user and carer involvement.

Leadership: Support and commitment at senior level helps drive a culture that supports ongoing and meaningful involvement. Representation on the organisation's board is also recommended, for example, via an executive director or board member with a user or carer background and/or a special interest. Similarly within services and teams, having 'leads' or dedicated staff for involvement can help establish the appropriate culture as long as it is clear that involvement is everyone's responsibility. Psychologists are well placed to

provide expertise in leadership, specialist knowledge and skills (e.g. training) and can link this to initiatives such as co-production or time banking (see Methods, p.??).

Accountability and monitoring: Responsibility for involvement should rest with the service or team who are accountable to the organisation (NHS Trusts are in turn accountable to the Department of Health – see introduction and background). Monitoring the implementation of the involvement strategy should be ongoing and findings reported. Service users' and carers' experiences of involvement should be monitored and any suggestions or concerns fed into the development process. Progress of involvement should be monitored through performance management, to which individual teams are accountable.

Within the organisation it can be helpful to establish a forum wherein people interested in user involvement can provide consultation as well as plan integrated initiatives. This forum should include service users and carers, perhaps linked to external organisations. Groups of service users and carers wishing to meet outside of the main fora should be encouraged with venues and mechanisms for feeding into other groups identified collaboratively

Other relationships: Beyond the immediate organisation, it is essential to forge relationships with local third sector and other relevant organisations including LINKs who have a role to play in reaching out to local communities and gathering views and experiences to influence how services are planned and commissioned.

This may provide further momentum and lobbying for involvement initiatives, highlight areas requiring the input of service users and carers and aid the recruitment, support and training of local service users and carers. Mental health charities and user groups often welcome collaboration with statutory services.

For example, MIND advocates that service users should have the opportunity to be involved in decisions about every aspect of mental health services – from their individual care and treatment to local and national policy.

They include the following in their manifesto for full involvement:

- Equal citizenship.
- Dignity and respect in mental health services.
- Full information on treatments and rights.
- Involvement in treatment and care.
- Independent advocacy in every area.
- Broad participation of users through equal opportunities employment and service delivery practices.
- Involvement in planning, running and evaluating services.
- Policies to ensure it is safe to get involved.
- Training of workers by users.
- Practical commitment and resources for user involvement.

Mind also has a large and active service user/survivor network – Mind Link – to provide ongoing input into Mind’s work.

Rethink run local and national service user and carer groups and services and state that involvement means ‘taking an active part through being listened to and contributing to processes’, including:

- Assessing personal needs and planning to meet those needs.
- Planning or reviewing care services.
- Running services.
- Involvement in quality issues, for example, evaluation.
- Education and training of professionals.

Rethink provides support to service users and carers interested in getting involved in sharing their stories to beat discrimination and campaign for changes to services.

‘INVOLVE’, as part of the NHS National Institute for Health Research developed guidelines through the TRUE project (Lockey et al., 2004), for those interested in research-focused training with or for service users.

The role of clinical psychologists

Professions such as nursing (e.g. Rudman, 2008) have highlighted the importance of mental health professionals being exposed to user and carer involvement ideals and practices throughout their training, and Soffe (2003) asserts that British clinical psychology generally needs to see involvement as its ‘business’. With expertise in organisational and attitudinal change, relationship building, managing power differentials, management, research, training and leadership, clinical psychologists can provide expertise or consultation on many levels. As they often hold key leadership, managerial and research positions within statutory mental health services, clinical psychologists employing involvement principles in practice and strategy may expedite greater involvement throughout the NHS.

Though involvement in an individual’s own care or therapy is often seen as essential, it is not assumed that all therapeutic modalities or therapists fully employ it.

And whilst involvement in individual therapeutic decisions is a necessary building block (in developing capacity for involvement in service users, carers and in services) it is not sufficient: involvement practice must permeate services beyond the consulting room.

Soffe et al. (2004) refer to potential power differentials between psychologists and service users in the therapeutic relationship, leading to the latter being at risk of being marginalised. They also elicited the fear from psychologists that further development of user involvement might render psychologists less useful – certainly key areas to be aware of when considering current and future involvement activities. Some clinical psychologists have undertaken extensive work within and with communities, furthering the social inclusion and citizenship agenda and the idea that mental health problems are not solely

located within the individual (Parker, 2007). For example, Fabian Davis (2010) writes of helping identify the ingredients that help people 'bounce back' from mental health problems and lists clubhouses and employment as key factors. He had previously interviewed service users about their perspective on community issues such as exclusion.

Part II: Starting on the right foot

Within services, there is often a desire and commitment to develop meaningful service user and carer involvement but this is often coupled with not knowing where or how to start. There are usually demands on time and resources together with an uncertainty of how to do it well. The intention has been to help clinicians take the first steps and to provide practical tools and advice to support effective involvement.

Part II of the guidelines covers:

- **Principles underpinning involvement.**
- **Obstacles.**
- **Supporting processes.**
- **Diversity in involvement.**

Principles

These were arrived at through asking clinical psychologists, carers and service users ‘what works’; and from applying ‘recovery’ principles to describe the perspective service users and carers may adopt if afforded more key positions of power in mental health services.

- Ask service users and carers how they want to be involved: establish a culture of partnership, inclusion and openness from the outset.
- Direct experience of mental ill health is valuable and can enrich professionals’ knowledge.
- Involvement should be values-led and must be inclusive, equitable, supportive, respectful, transparent and open, acknowledging and valuing diversity.
- Involvement should aim to be service user- and carer-led, for example, determining research/consultation questions rather than simply responding to consultations.
- Power differentials should be acknowledged and participants should strive towards partnership, being service user- and carer-led.
- Consultation is necessary but not sufficient to render an initiative ‘involvement’.
- Build links within and outside of the organisation(s) participating.
- Involvement should occur at every stage of an initiative.
- Involvement initiatives should be documented, evaluated and reflected upon so that learning is not lost with feedback on its impact being given at every stage.
- Involvement should be iterative and follow the act – evaluate – reflect – learn-act cycle.

Top tips:

- Start small and grow.
- Capitalise on existing support.
- Provide support.
- Be clear about the realistic impact of the involvement initiative.
- Disseminate reports of the impact of involvement initiatives.
- Be clear about payment(s) available.
- Be sensitive to the practical needs of service users and carers (e.g. meetings held in the afternoon, providing healthy refreshments).

- Consider individuals' fears that their health care may be affected by getting involved.
- Engage multiple service users and carers to provide continuity of representation.
- Provide extra support (e.g. printing papers, training, debriefing and planning sessions).
- Target all stakeholders (e.g. community leaders).
- Utilise multiple data gathering techniques (i.e. not relying on one method).

Obstacles to negotiate in user and carer involvement

When service user and carer involvement is discussed, obstacles to its progress are commonly raised. These tend to be quite similar across a range of different activities. This section aims to identify some of these and suggest ways of managing them.

Representativeness:

The recognition that one service user cannot represent all service users' views. This does not appear to be a barrier for professionals (one psychologist cannot represent all psychologists) and there is some evidence (e.g. Crawford & Rutter, 2004) that service users who are 'involved' have similar priorities to those who are not actively 'involved' in activities. Though it should be aspired to, delaying action until 'representativeness' is achieved may cause loss of momentum or interest in the matter under consideration. See the *Good Practice Guidelines for Service User and Carer Involvement in Clinical Psychology Training* (DCP, 2008) for further discussion.

Tokenism:

This refers to the concern, often held by professionals and service users and carers alike, that involvement is not meaningful or genuine, 'rubber stamping' decisions already made, for example. Ensuring that service users and carers are involved from the beginning, are supported with appropriate training and information, that the remit and terms of the engagement are clear (and drawn up in collaboration with service users and carers) and the outcome of the involvement initiative is reported back to stakeholders can make the process transparent and allow people to 'opt out' if they are unhappy with the process.

Difficulties in concentrating:

Do not assume that this will be a problem, but where people are adversely affected by side effects of medication or symptoms consider different involvement mechanisms, and timings, provide support, training and information in a number of formats, check people's understanding and invite questions throughout the process.

Communication:

This is often cited as a problem given the prevalence of jargon and abbreviation. Transparency and plain English are likely to benefit all present in a meeting. Providing training and/or a guide to terms before commencing the process is also likely to benefit people other than service users. It can be helpful to bear in mind that questioning of terminology and assumptions is one of the benefits of involving service users and carers (Harding et al., in press).

For example, individuals invited to comment on a screening tool, particularly the wording and the terms used when discussing cancer.

‘Over dependence’ on one or two people:

The apparent lack of interest in the initiative from wider service users and carers may be compensated for by relying on a small number of highly involved individuals. In this case, consider the attractiveness of your involvement aims, opportunities, remuneration and recruitment practices. Employing a ‘snowball technique’ for garnering new interest may increase attendance. However, the people already getting involved are likely to be motivated, skilled and effective and may open the door to others getting involved. They may also be interfacing with other service users and representing others views already and may be encouraged to do so if not.

‘We cannot meet the demands we anticipate’:

Not involving people because the service can’t meet all of their requests risks missing out on valuable learning, empowerment and collaboration. A forum where people are invited to express preferences, demands and concerns may enable service users and carers to respond to limitations (e.g. funding) with new suggestions. Being clear about these limits, and the scope of the initiative from the start, is good practice, as is not making promises that cannot be realised. The possibility that presently unattainable goals may be generated by service users should not be a reason to avoid involving them, communicating difficulties with suggestions after they have been genuinely explored and maintaining them as aspirations may have a positive impact on the relationships existing between staff, service users and carers.

‘We know what they want anyway!’

Some professionals may be aware of some issues important to local service users and feel able to represent them themselves. However, this separates the individual from their right to have a say in decisions and there is no evidence that professionals have anticipated the needs, views or preferences of the service user and carer population in that particular instance. There is value in the process as well as the outcome of involving service users and carers.

Staff attitudes:

Involvement is increasingly a part of the training in many professions but practices and enthusiasm differs between individuals. As such genuine involvement may require a significant attitude change among people at several levels of the organisation. Psychologists are typically process experts and have considerable knowledge about attitude change. They are well placed to recognise the difficulties associated with any organisational culture change and to provide support and consultation themselves. Psychologists may be encouraged to develop an involvement forum to provide peer support across departments within individual organisations.

Organisational obstacles – lacking time or money:

Beyond any ethical imperatives, the Department of Health is serious about change, which needs to be both top down and bottom up. It is useful to start small and capitalise on existing support. The extent of service user and carer representation varies across organisations but Patient and Public Involvement leads are located within each NHS Trust. Identifying (or developing) organisational policies and procedures and utilising incentives (e.g. good practice awards) can build relationships and generate momentum. Involvement can be about working ‘smarter’ and being more in tune with demand thereby making best use of resources. Eventually, PROMS (Patient Reported Outcomes Measures) and payment by results will make it more difficult to access resources without being able to demonstrate effective involvement strategies

Supporting processes

The following processes are useful to underpin an organisation or service’s involvement strategy.

Payment policy:

Given the complex and shifting nature of benefits regulations it is not possible to produce a comprehensive payments policy here. It is recommended that each organisation develop its own, in collaboration with service users and carers. Principles that this should rest on include:

- Appropriate levels of payment should be offered for meaningful work – including consultancy fees and expenses, and monies in the service of skills that the individual has used for the piece of work. As such, facilitating a focus group should attract a higher rate of pay than participating in one given the skills required. ‘Meaningful work’ refers to ensuring that activities are pertinent to the involvement task at hand and do not exist merely to give people something to do.
- Rates of pay and expected hours of work should be made clear at the outset of any involvement initiative.
- People should be made aware that accepting payment is likely to impact on their benefits entitlement and that individuals may wish to seek advice (giving contact details of a local benefits advisor, if available).
- The option not to be paid to avoid benefits being affected should be offered.

Further guidance is available from *Reward and Recognition* (DoH, 2006).

Training and development:

Training should be offered to service users and carers (from the involvement team or local service user/carer stakeholder groups) to enable them to participate fully in involvement initiatives (e.g. in a research methodology or terminology) but should not be used in lieu of actual involvement. Service users and carers should be asked what training they feel they require at the outset and appropriate training arranged. Where possible service users and carers should deliver the training and it should be evaluated and learning shared. Service users and carers should be supported to develop their own training rather than deliver pre-determined programmes.

The South London and Maudsley Involvement Register enables service users to observe different types of involvement in action, to help them decide the level they feel comfortable with undertaking themselves. Peers contribute to selecting appropriate people for each project; the match between skills, confidence and the task is aimed at increasing the genuineness of involvement activities and building individuals' skills and confidence.

Information and support:

This should be accessible (available in different formats), use plain English, be jargon-free or provide a guide or training to demystify jargon used; be provided using multiple means of communication; it should include briefings and pre-meetings, and adhere to principles enforced by the Disability Discrimination Act (1995, 2005). The use of advocates, mentors and/or buddies, and personal assistants as well as service user/third sector organisations can make involvement more inclusive of difference,

Complaints procedure:

This should be planned, specified and publicised with individual complaints responded to with appropriate action taken after impartial investigation.

The involvement of diverse groups of service users and carers

Minority groups have unique needs and are often under-represented in mainstream policy and guidance on service user involvement. It has not been possible to incorporate data pertaining to all possible recipients of clinical psychology but it is suggested that the broadest demographic variables (age, gender, ethnicity, sexuality and intellectual disability) have been highlighted. It is worth noting that, whilst there may be specific issues for particular groups, there are many common themes when seeking to meaningfully engage with people: tailored support; advocacy; flexibility; appropriate communication; trust and feeling safe; time; resources; training (for staff and service users); genuine 'voice' and influence; support at senior level; feedback on outcomes; engaging with (specific) communities; and a focus on citizenship.

In any involvement initiative, it is important to ensure and promote the participation of all relevant groups. This should be considered at the planning stage and may involve specific outreach work to engage with particular groups.

For example, the SpeakOut Network provides a bridge between the regulator and seldom-heard communities. Members contribute to regulatory processes by participating in studies and reviews and submitting feedback forms.

The Care Quality Commission advocates services reaching out to BME communities to find out how they would like to shape their services, given the overrepresentation of people from BME backgrounds that are involuntary detained. (CQC response to the Mental Health Act Commission's biennial report, 2007–2009.)

The SURP – Service User Reference Panel which consists of service users undertaking joint visits of services detaining people under the Mental Health Act seeks to ensure its service users are representative, each of them has current or recent experience of detention under the Act themselves.

Duties under equalities legislation need to be borne in mind, including positive duties to enable people with particular needs, for example, with disabilities, to take part in public life.

C. One service developed a non-psychology-specific group for parents and carers and are in the process of developing a child service user group.

Carers:

Carers and service users are recognised as having differing, sometimes incompatible views, for example, on the provision of confidential information (e.g. Goodwin & Happell, 2006). Carers may also have other barriers to their effective involvement. These include lack of financial and other recognition for their services, pressures on their time and feeling disenfranchised through being expected to provide the bulk of home care whilst being kept out of the information ‘loop’. The lack of research concerning carers’ preferences and needs (DoH, 2002) complicates the process of determining what works for them. However, Department of Health (2002) guidance on developing services for carers suggests that services should be ‘accessible, responsive and individually tailored to their needs’ (p.8).

Given that many carers of people with mental health and psychological needs perform this vital role ‘behind the scenes’, it may be necessary to outreach to them. Carers themselves may have mental health needs but not seek help; facilitating opportunities for carers to be assessed and assisted may lessen this dual burden. The wider impact of caring on carers’ lives, such as on financial, educational and career-related activities also requires careful consideration.

L. One group developed a carer’s specific support group.

Lesbian, gay, bisexual and transgender (LGBT) service users and carers:

The King’s Fund commissioned an evaluation of a mental health advocacy project (PACE) for the LGBT community in 2008. Its findings have some relevance for the inclusion of the views of LGBT service users and the ‘empowerment’ of this often ignored sector of the service-using community. Ingredients in the success of this, and presumably future involvement initiatives include individuals trusting the service not to judge them and to ‘help them negotiate with a world they feel and know can be ignorant and hostile towards them’ (p.5). Having multiple forms of advocacy (from ‘peer advocacy’ – being supported to speak up by people experiencing similar problems) to ‘citizen advocacy’ (whereby a trusted ‘valued citizen’ speaks up for the disenfranchised individual or supports them to do

so themselves) may increase the chances of an individual finding a mode that suits them. Advocacy and ‘speaking up’ are essential to involvement – providing an appropriate environment may enable LGBT voices to be heard. Areas highlighted as being specific to success for LGBT service users and carers included:

- Positive role modelling.
- Providing a safe space.
- Removing barriers.
- Honesty.
- Eliciting trust and confidence.

(Adapted from the King’s Fund, 2008)

Older adults:

The Care Service Involvement Partnership (CSIP) developed a service development guide to integrating mental health services for older adults (2005). Its recommendations centred on the changes that need to happen within services to prevent older service users and carers being excluded from decision-making because of assumptions made by some individual service providers that they are incapable. The central tenet of the suggestions made refers to the philosophy that ‘if people can communicate in some way, however difficult it may be they are encouraged to do so’. As such, involvement – as a form of communication – is unlikely to be straightforward. They add that carers’ views are vital, both ‘in their own right as well as on behalf of people with mental health needs’.

Suggestions to increase communication with older individuals and carers include:

- Viewing involvement as an ongoing not a one-off process.
- Training everyone in communication skills.
- Providing service users and carers with appropriate support, advice and encouragement.
- Ensure appropriate mechanisms for users and carers to genuinely voice their views.
- Provide appropriate funding.
- Train staff in involvement skills.
- Allow enough time for effective involvement.
- Provide feedback on the outcomes of involvement initiatives.

(Adapted from CSIP, 2005)

People with learning disabilities:

A local publication from a service in Lincolnshire outlined the content of two conferences including service user-led presentations themed ‘what speaking up means to me’ (Dorr, 2000). This provided the basis for an involvement initiative. Various types of involvement are listed that can slot into one of five levels – ‘giving information’, ‘consulting’, ‘deciding together’, ‘acting together’ or ‘supporting independent community interests’. They suggest these five levels may be viewed either as ways people develop their own power and responsibilities or as the appropriate level of participation that the initiative is operating at. Giving information is described as vital to help people making choices but it casts the giver as ‘expert’ though users and carers could also be the information givers. Consultation allows choice between limited options. Deciding together suggests that people negotiate decisions from positions of equal weighting. Acting together helps people identify solutions and implement them, with key ingredients being trust and equality in power and

resources on all sides. These dimensions simplify Arnstein's ladder (1969), and include action as an aim. They are consistent with suggestions below that having a limited number of choices may, for some decisions, be optimal. 'Valuing People' is the Government's strategy for improving the lives of people with learning disabilities, that describes the importance of individuals' recognition as citizens, consumers and voters. However, there is a need for broad yet specific policy and guidance concerning involving people with learning disabilities on a level.

Women:

Into the Mainstream (DoH, 2002) was a consultation document on women's' mental health issues. The Department of Health published responses to the document in 2003. One specific area respondents were invited to consider concerned how 'gender and other dimensions of inequality (should) be addressed in training for mental health practitioners'. Responses suggested:

- Women should be involved in commissioning, well-resourced patient councils and forums (sic), their own care planning and treatment decisions and clinical governance.
 - Appropriate advocacy should be available to all
 - Training should be provided to professionals in relation to their value-base with regard to gender issues and development of skills in working in partnership with women service users and working from the principal of recovery (sic).
 - A clearer strategy for empowering women working in mental health services should be developed.
 - There could be a senior key person with lead responsibility for ensuring that gender issues are maintained as a fundamental part of the organisational structure.
 - Sensitive training is needed.
- (Adapted from DoH, 2003)

Children and young people:

Day (2008) wrote a comprehensive paper highlighting areas of knowledge and practice that serve to encourage children and young people's involvement in both clinical processes and service development. These include the premises that:

- Goals should be clear and involvement instrumental, not the end point in itself.
 - Clear explanations about the purpose, mechanisms and hoped-for outcomes should be given.
 - Participation should be meaningful, possibly achievable through sensitivity to participants' developmental stages and offer appropriately limited (rather than endless) choices made possible by providing sufficient information.
 - Children and young people should have their own voice rather than be used to give legitimacy to others' decisions.
 - Senior support should be garnered.
 - The impact of initiatives should be assessed.
- (Adapted from Day, 2008)

Black and minority ethnic service users:

'Dancing to our own tunes' (NSUN, 2008) explored black and minority ethnic and white British service users' experiences of involving and being involved in developing services together. Barriers such as racism, stigma, power relations, exclusion from setting the direction of involvement initiatives and the absence of appropriate support, remuneration and information were emphasised. Achievements were noted to have emerged when user groups were set up independently of mainstream initiatives and this was linked to separate groups being able to set the 'parameters of involvement' (p.3) themselves.

Recommendations designed to increase the effectiveness of involvement initiatives for black and minority ethnic groups included:

- Linking involvement work to wider race and rights focused initiatives (e.g. education, forensic services, employment).
- Focusing on building relationships between communities, service users and professionals.
- Encouraging black and minority ethnic mental health professionals to consider race-related issues in their own work.
- Supporting local agencies to work independently and to access sustainable funding.
- Refocusing attention to the individual's social role rather than on their mental health.
- Increasing networking.
- Providing opportunities for service users to be mentor and be mentored by other service user involvees.
- Evaluating initiatives based on outcome rather than content and process and disseminate lessons learned.

(Adapted from Jayathil/NSUN, 2008)

Service users in secure settings and their carers:

The NHS Forensic Mental Health Research and Development expert paper on involvement (Faulkener & Morris, 2003) points to fundamental difficulties for service users and carers seeking involvement in or from secure settings. Areas highlighted included the role of security and confidentiality in such services and the 'culture of fear' created by the development of dedicated facilities for those who attract a diagnosis of 'dangerous and severe personality disorder' (p.13). The traditional 'patient's council' and variations on this theme were generally reported to have 'lost the confidence of both patients and staff' (p.14).

Emergent mechanisms whereby people in secure settings are able to have their views made known to key decision-making personnel via advocacy or in-reach staff were described and may help overcome the barriers identified above.

The Mental Health Act Commission (now the Care Quality Commission) developed a range of involvement initiatives aimed at engaging people with experience of being detained under the Mental Health Act in all aspects of the Commission's work. A Service User Reference Panel of around 30 people with current or recent experience of detention (including in secure settings) was set up working mostly – although not exclusively – 'remotely' by post, e-mail and telephone.

Part III: Taking the bull by the horns

As stated earlier, involvement can be seen as a way of doing things – a culture – alongside specific initiatives. The intention in this part of the guidelines is to provide resource-rich information and advice to help services, service users and carers initiate, plan, carry out and evaluate involvement initiatives. As well as describing different methods and numerous examples, a checklist to gauge organisational capability for involvement, a profiling tool to provide a ‘high level’ assessment of the levels and gaps of involvement in services and a simple planning proforma are included.

Part III consists of:

- **Starting out**
- **Methods**
- **Evaluation**
- **Conclusions**

Starting out

As an underlying principle (see above), service users and carers should ideally be involved from the start (in generating ideas for change) and throughout the involvement cycle – from scoping, mapping, determining ‘first’ or ‘next steps’, planning initiatives, carrying them out and evaluating, learning from and disseminating them.

When thinking about involvement, it can be useful to undertake a scoping exercise (1) to ascertain what is already available and in place, a mapping exercise (2) to determine priorities, and a plan (3) to support the development of specific initiatives:

1. Scoping exercise: Gauging capability and capacity for involvement.

When initiating involvement, a scoping exercise to assess the current involvement picture, become familiar with or develop organisational policies and procedures, identify funding, and stakeholders and build relationships with local organisations can prevent unnecessary duplication of work and establish support. Service management and involvement leads should familiarise themselves with organisational policies and procedures and local levels of involvement activity when starting out to avoid unnecessary repetition of work and identify available resources.

When considering a new involvement initiative, it is helpful to gauge current capacity and build in resources where they are lacking. The following outlines 10 important building blocks (which are provided in a checklist format in Figure XX) that enable effective involvement, particularly from the perspective of service users and carers. The list is not hierarchical or exhaustive and the aspects are inter-connected:

1. There is an organisation-wide strategic approach to involvement: In response to the policy drivers outlined above, both broad brush and service-specific strategies should be in place to provide a framework and motivation to engender further service user and carer involvement.

2. Service users and carers are genuinely able to generate and influence salient issues throughout the organisation: Service users, carers and staff have at least an equal opportunity to have their views heard and incorporated into decisions and priorities. This includes the notion that decisions should be made with all service user and carer opinions in mind, with even those countering ‘hoped-for’ outcomes being genuinely considered and all issues that affect service user and/or carer welfare are open to service user and carer scrutiny.
3. Service users and carers have ownership of involvement within organisations: There are clear mechanisms and processes in place that support service user and carer ‘ownership’ of involvement which include setting priorities, development, implementation, evaluation and oversight. Professionals representing services should be open to discussing the aims and principles of the individual or overarching involvement strategy (Faulkener & Morris, 2003).
4. Individual services, departments and work streams are responsible for implementing their own involvement initiatives. This can range from front line services to supporting functions such as clinical audit, research and development; Human Resources. Frontline services should be supported and encouraged to be responsible for involvement on ‘their patch’ using their creativity and knowledge of the locality. Specific links between involvement and the role and remit of clinical psychologists could be outlined.
5. Involvement is embedded within performance monitoring at all levels: As well as responding to LINKs and Care Quality Commission reports, organisations should meet their own locally determined standards which may be linked to budgetary demands and other drivers. Involvement in this context could focus on the experience and views of people receiving services and their carers and should be geared up to ‘user-defined’ outcomes.
6. Reciprocal relationships with key stakeholders are in place: As outlined above, third sector organisations often have wide service user and carer membership including people who are keen to get involved and skilled in doing so, and can be enabled to provide another support and training function. Mental health charities often run their own services (e.g. Rethink’s advocacy services) that are experienced in working with other agencies.
7. Diversity and difference are valued and integrated into involvement initiative plans and personnel to improve their application and appeal: Whereas ‘representativeness’ of all possible voices cannot often be achieved, encouraging ‘harder to reach’ service users and carers to have their say and actively seeking to hear from all parts of the community should be built into involvement initiative plans and strategies.
8. Training and Development opportunities are available to support involvement: This can be applied to staff and service users and carers alike and can include induction, training courses and supervision; user and carer-led training is available with service users and carers leading on the content and delivery of training packages as far as possible.

9. Resources: dedicated monies and personnel are available to resource involvement initiatives: As detailed above, service user and carer involvement is not seen as an add-on, but an integral part of financial and human resource provisions for each service.
10. Evaluation is typically built into involvement plans: and feedback as to how ideas are being implemented is prioritised. This should examine how service users and carers have been involved in the past, its success and the learning that emerged to enable good practice to be shared and genuine learning to take place.

Building Capacity Checklist

- 1. Organisation-wide involvement strategy in place which interfaces with individual services, departments and work streams.
- 2. Mechanisms in place to ensure service users' and carers' views are genuinely able to influence salient issues, for example, through LINKs, Board leads, formal consultations, governors.
- 3. Mechanisms and governance processes in place to support service users and carers having ownership involvement initiatives, for example, service user council, involvement steering group, service user workers.
- 4. Individual services, departments and work streams are responsible and accountable for implementing their own involvement initiatives
- 5. Involvement is embedded within performance monitoring throughout the organisation.
- 6. Reciprocal relationships with local service user and carer organisations, advocacy services, community groups and voluntary organisations are in place.
- 7. Diversity and difference are valued and routinely integrated into involvement initiatives to improve their application and appeal.
- 8. Training and development available to support user and carer involvement.
- 9. Involvement-dedicated personnel and monies are available to resource involvement.
- 10. Evaluation of involvement is typically built into work/project plans.

2. Mapping local involvement: What's currently happening; where the gaps are.

Domains of involvement

Involvement occurs across four domains within an organisation or service (Perkins & Goddard 2005): individual (inclusion in decisions about the person's treatment, for example, goals to aim for and frequency of contact); strategic (involvement in deciding the direction of services and how they are developed, for example, when and how to amalgamate teams); operational (involvement in deciding the day-to-day operation of services, for example, which staff are appointed) and evaluative (feedback on the service obtained directly from service users and carers, for example, questionnaires, surveys, focus groups). The guidelines particularly focus on the involvement of service users and carers at service level but, as the four domains are inter-connected, also consider how this aspect of involvement interfaces with individual, strategic and evaluative domains.

Where the service has not identified any specific areas to be addressed, involvement should be ongoing through the gathering of feedback and the identifying and utilising service users' and carers' concerns, hopes and expertise regarding the individual service (the 'evaluative function'). If this is infrequent, consider whether individuals are given the opportunity to comment and how their feedback is responded to.

A planning tool has been developed by Emma Harding and colleagues (see Planning Tool, Appendix A). The red domains, in which the service most deviates from the dashed square, may usefully be prioritised. As such, involvement should become embedded within the organisational culture and climate and be supported by staff and management (see Figure 1, p.??).

For example, N, the NSF Local Implementation team is chaired by 'black sisters' voluntary organisation.

3. Planning

The scoping exercise can assist in identifying the current capability and capacity within organisations for involvement and the mapping tool can be used to identify priority area(s) for involvement within services. Clearly good planning is key to the success of any initiative. Clinical psychologists have relevant and well developed skills for assessment, planning and evaluation. This section, together with the simple pro forma [DN: need ref], is intended to provide a structure or a guide for planning involvement initiatives, particularly from a practical viewpoint to facilitate clarity about who is doing what, why, when and how.

The question – defining the purpose of the initiative:

Service user and carer 'ownership' of the aims, process and outcome of any intervention should be the ultimate goal. Involvement should be an immediate priority at times of change to the service (e.g. to staffing, service configuration, local or national policy, the physical surroundings or when a local incident or event is to or has taken place), with mechanisms for input already in place.

The 'question' should be open and ideally designed to elicit qualitative information as well as any necessary quantitative data. Where a specific aspect of the service is being explored it should clearly reflect this. Service users and carers should be involved in initiating and developing the question, for example, via a focus group. Existing or specially convened groups can both be used in this context. As described above, some groups of people (e.g. children and young people) may prefer a list of options to choose from rather than generating their own ideas. Consideration of limits to funding/resources should be given when responding to suggestions made, though stating that all options will be investigated fully and feedback given at a later date rather than dismissing ideas is recommended. The scope of the initiative should be as inclusive as possible to avoid prompting unrealisable expectations or imposing unnecessary limitations.

Leads and oversight:

Identifying key personnel with professional, service user and carer affiliations and planning or making use of links with local stakeholders (such as local service user and carer groups) can help identify both champions and those who can carry the initiative(s) forward.

Partners and links:

Working with others, both internally and externally, can help involvement initiatives have more impact. As well as working with the organisational PPI team, other internal links could be, for example, with equality and diversity, Human Resources, R&D, IT, finance. More widely, as well as the aforementioned LINKs and service user and carer groups, community groups and the research community can be useful partners depending on the nature of a particular initiative. It is important that all stakeholders develop a common understanding of the purpose and nature of the planned initiative.

Resources:

Once resources have been identified, developing a simple budget will help ensure the project is sufficiently viable. This should cover expenses and payments to service users and carers where appropriate. Bids should allow for the payment of service users' and carers' fees and expenses (see payments policy, 'starting out'). These should allow for extra time and support for preparing for meetings and for accessible materials.

Methods:

Having some clarity from the outset about the scope of the project and changes that might be possible and methods for generating interest, collecting and working with the data as well as how to implement and disseminate findings can be akin to those undertaken in most research projects. Enabling service users and carers to influence the design and these other aspects of the initiative (including evaluation) can build interest and engagement. Further information about methods and examples are provided in Part III.

Support, training and communication:

Asking service users and carers about the support they need to fulfil the agreed task and providing appropriate funding and training is key to the success of involvement work. This can include training, (accessible) information and meeting particular communication needs, for example, through an interpreter or advocate. Organisational policies and processes, for example, payment policy, equalities scheme, should be identified and followed (or adapted if needed). Feeding back the outcomes of the project especially when they are different to those anticipated is crucial to build trust and genuineness.

Evaluation:

Evaluating how well involvement worked can help improve practice in relation to involvement as well as facilitate ownership of involvement by service users and carers. This can be both ongoing, for example, through simple verbal or written feedback, or a more structured assessment. Particularly with the latter, an independent and/or service user/carers-led evaluation could provide more honest results.

Methods

'Real Involvement' also refers to different levels of involvement constituting 'the involvement continuum'. This document describes the different levels as well as providing information about techniques and checklists. It also provides a detailed account of service user, patient and public involvement in the commissioning of services relating strategic issues, for example, establishing local needs and priorities, managing performance, to operational approaches to involvement, for example, identifying stakeholders, working with LINKs, or setting up a specific forum or panel.

Embedding involvement across the four domains of involvement (Perkins & Goddard, 2005) can be approached from a variety of directions. Approaches that have been documented for use include but are not restricted to:

Consultation:

Before any transitions (e.g. starting therapy, changes in organisational structure or staffing etc.; service users and carers should have a formal opportunity to express their views, which should be considered when decisions are made. It should be remembered that there is a legal requirement in the NHS Act 2006 to consult and involve service users and not just when substantial changes are proposed. There is a Government *Code of Practice on Consultation* (DoBERR, 2008) which outlines seven criteria such as clarity of scope, accessibility and responsiveness and which should be followed for all public consultations.

Even where no changes are imminent, service users and carers should be routinely consulted by staff as to their experience of the service and suggestions for alterations and improvements considered.

All clientele were invited to an open meeting held by a staff team in a local support and recovery team. From discussions, a request for a regular social forum became a 'coffee morning in the afternoon' held on a monthly basis.

A clinic employed an external agency, options UK to carry out a thorough consultation specifically including harder to reach parts of the community when moving premises.

Co-production:

This group of methods recognises the assets individuals bring to supporting one-another and to the delivery of services – both formally and informally and as members of staff.

For example, C, A post designed for a service user to assist in the running of a monthly recovery group.

For example, SCIE, The Keyring scheme enables professional and volunteer carers to support a group of people to live in their own homes and facilitates communication between members. Needham and Carr (2009).

For more information see Needham and Carr (2009) *SCIE Research briefing 31: Co-production: An emerging evidence base for adult social care transformation*.

User groups and non-governmental organisations:

User organisations often have a broad membership and are keen to cultivate partnership working with the public sector. They can provide training and support to service users and carers involved in activities benefiting both parties. Disconnection from the wider local and national context risks failure.

Mental health charities often provide advocacy services as an inreach to NHS Trusts. For example, Rethink provides advocacy via over 250 services to inpatient units, secure hospitals and via patients' councils. This includes providing IMHAs (Independent Mental Health Advocates) to enable people to make decisions.

Time banks:

In lieu of payment for work undertaken, service users and carers can register with a time bank and receive services in kind. These can be used in conjunction with co-production.

South London and Maudsley NHS Foundation Trust works in conjunction with timebanks utilising the concept of 'mutual volunteering' – exchanged for training courses and other commodities.

The Commission for Social Care Inspection has involved 'Experts by Experience' – people who use services – in their inspections of adult social care services since 2006. Experts by experience are from a diverse range of backgrounds and receive guidance and training.

'Acting together' visits are provided by the Care Quality Commission in partnership with users of mental health services. Service users in this context are those who are, have recently been detained under the Mental Health Act and are each members of SURP – the service user reference panel. Commissioners and SURP members plan and carry out visits together and are both provided with appropriate training.

Creativity and an awareness of the needs and interests of local service users and carers mean that the possibilities are unlimited. Other methods include:

- Feedback processes (beyond electronic data gatherers): Dedicated meetings, questionnaire survey and, trainee service evaluation research are appropriate mechanisms, it can be helpful to determine appropriate points at which data is routinely gathered – for example, transitional points between services or types of care.
- Advocacy: As well as independent advocacy services, befriending organisations can help people's voices to be heard and can build trust between an individual and the service they are working with. This can further build confidence and links with the community.

- Membership of committees: Local service user and carer groups often feed into services on a range of levels and benefit from active participation. This can ensure service user and carer perspectives are represented, performs a lobbying function and can in turn lead to individuals gaining skills and confidence.
- Discussion groups: Even where no particular change is underway, groups of service users and carers can meet to build local links, share expertise, develop a different relationship with services and provide a forum for addressing more concrete issues (such as possible changes) when they are first suggested.
- Surveys, questionnaires: As above, these can be routinely conducted at transitional points and by trainee clinical psychologists.
- Focus groups: Ideally following the user focused modelling method (Rose et al., 1998), these should be facilitated by service users who have received training and can form part of the process of developing local service user and carer-relevant monitoring questionnaires.
- Campaigning groups: These can form around particular salient issues and can be used to lobby services, local service user and carer third sector organisations and the government or can campaign on local matters (e.g. discrimination, access to local amenities, etc.).
- Interests groups, for example, art, drama: These should be led by and responsive to demand and as service user- and carer-led as possible.
- Service user and carer experts/consultants/activists: Training, support, debriefing and feedback should be easily accessible. Some service user and carer organisations provide training for people interested in working with the media to promote service user and carers' perspectives (e.g. Rethink offer support and training to media volunteers including an online resource and booklet entitled *You and Media*).
- Service user and carer research and researchers: Research can often be informed or conducted by service users and carers. Ethical approval is often contingent upon service user and carer involvement in its development, the gold standard being where service users and carers determine the research question, if not gather, analyse data and disseminate findings (which should be implemented where relevant).
- Service user and carer employees: All employers are subject to the Disability Discrimination Act (1995, 2005), it is contended that service users and carers should be employed because of, rather than despite their personal experience (Perkins et al., 1997).
- Employment support: In-house or in-reach support can enable service user and carer employees to maximise their potential. This may help meet DDA (1995, 2005) requirements and standards called for by the social exclusion unit report (ODPM 2004). This support is often available from third sector organisations (e.g. QEST).
- Peer support: Providing venues and administrative support or facilitation for service users and carers to meet can act as a foundation for other enterprises listed here and enable the sharing of expertise and skills.
- Service user and carer mentors/buddies: When an individual is joining a new service, post or intervention, contact with someone who has previous relevant experience can build confidence, engagement and trust. The service user/carer buddy or mentor can also benefit by gaining skills and confidence and may be encouraged to trade this experience in a local time bank and receive a service in return.

- Service user and carer trainers: Training, where possible should be service user and carer developed and led and targeted at both lay and staff populations. Local organisations such as CAPITAL (Clients And Professionals In Training and Learning, in West Sussex) can support individuals and organisations to build skills through training.
- Dedicated involvement personnel: Depending on the size of the organisation, an individual or team should lead on involvement issues, taking care to build capacity for teams to undertake their own involvement initiatives rather than take responsibility for it themselves. This may look like organising training or providing consultation to teams on the ground floor.
- Service user and carer representation on the organisation's board: This should ideally be undertaken by service users and carers themselves, though the involvement lead may be able to act in this capacity until more formal representation is arranged. Abovementioned suggestions for support and reimbursement should apply, whatever the skill level of the individual(s) concerned.
- Service user- and carer-led performance monitoring: Service users and carers should be involved in determining the indicators, tools, data gathering and analysis, using user focused monitoring and research skills where possible.

User focused monitoring (UFM) developed by Rose (1998) uses service user and carer priorities elicited in service user-led focus groups to develop tools such as questionnaires to measure the effectiveness of individual services on points that are meaningful to service users and carers themselves.

South West London and St. George's Mental Health Foundation Trust pioneered the supported employment of service users within its clinical and its administrative services since 1995. Year on year, 15 per cent of new recruits have disclosed having personal experience of using mental health services. In 2008 this figure had risen to 23 per cent.

Milton Keynes Community Trust decided to use web mail to facilitate feedback and information sharing. This came as a response to service users not being able to attend meetings and wishing to access information coupled with limitations on the service' capacity to reimburse travel expenses. Service users and the general public are able to post comments on it. The service also has a postal feedback clients are able to use on discharge.

For example, A, Leicestershire Partnership NHS Trust, working as part of an inter-agency Training and Development Strategy Group, set up a social enterprise (Inspired) in 2009 to employ service users as trainers. At present there are 10 service users on the board and a further six who also contribute to training. All involved service users have received training in training methods themselves and have thus far contributed to courses ranging from 'Good Practice in Mental Health' (using the Recovery approach) and 'Aspergers Awareness and Strategies for Support' to 'Racial Equality and Cultural Capability'.

Evaluation

As well as generating research into involvement processes and accessing service users' and carers' opinions about services, involvement projects themselves should be evaluated and learning disseminated. This ensures that work is not repeated and that projects are well planned, promote inclusive practice, and achieve the aims determined by service users and carers at the outset. Obtaining objective and systematic feedback should be embedded within the culture of mental health services and form part of the audit and performance monitoring cycle (see 'Starting out') but should not replace other forms of involvement. Feedback should contribute to the evolution of service provision rather than lead to transient services.

Evaluation mechanisms should aim for the following:

- To be service user and carer led; this is the 'gold standard' and enables meaningful aspects of the project's performance to be subject to scrutiny by those it seeks to impact upon.
- Data being gathered formally and informally, both on service effectiveness and patient experience.
- Feedback should be gathered and considered at every opportunity and fed back to all users and carers within the service, beyond just those who gave feedback. Where feedback or suggestions are not acted on, clear reasons why should be outlined at the earliest opportunity. This enables a culture of openness, though multiple other mechanisms need to be in place, for example, local and national external monitoring such as that conducted by LINKs.
- Feedback systems should be methodical, meaningful, purposeful and support a move towards an open feedback and choice culture, providing fora that offer genuine opportunities to relate and improve the general 'patient experience' of services as well as more targeted interventions.
- Findings should be disseminated and reflected upon.
- Similarly, research, as distinct from evaluation, should be led by or involve service users and carers at every stage – from design, data gathering, analysis, and dissemination. Service user and carer research should embody the principles of clarity/transparency: accessibility and diversity – with support and training being key (Morgan 2006).
- Trainee clinical psychologists' service evaluation research projects should refer to how the aspect of the service discussed impacts on the involvement of service users and carers if the audit itself is not primarily concerned with user and carer involvement.

Conclusions

Giving involvement dedicated personnel and funding, using both formal and informal involvement mechanisms, supporting local user and carer groups and building 'hard' and 'soft' skills for all stakeholders may enable involvement to permeate throughout mental health (and other) services and increase its permanence. The points listed above represent a condensed account of the priorities, spheres of interest and optimal ways of engaging service users from a variety of demographics. Many of them are applicable across the board

though underpinning philosophies may differ. They may be viewed as a ‘pick and mix’ set of technologies that can be tailored to meet the needs of the appropriate group or service. Some mechanisms of involvement are particularly relevant to one or two ‘special interest’ groups, but the importance of including diverse views and ensuring services are culturally relevant is apparent, though not necessarily straightforward. Flexibility and creativity are consistent to each perspective.

Though examples of involvement guidelines abound, there is a relative paucity of research evidence pertaining to the links between process and outcome of involvement mechanisms. Though it is acknowledged that some important service user-led research into involvement is already underway, with the apparently contradictory drivers for services to become more recovery and involvement oriented whilst demonstrating that they are evidence-based, further research is needed. And with the values that draw many people to the profession of clinical psychology resonating with the ideal of service user and carer involvement, the message is clear – that clinical psychologists should work alongside and for service users to develop, carry out, disseminate and learn from further research into involvement practices.

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Appendix A: Service User and Carer Involvement Profiling/ Planning Tool

Name: _____ Date: _____

Service mapped: _____

Involvement means services working in partnership with service users and carers so that their views, ideas and preferences decide what happens within, and to the service itself. This can be in one of four domains: individual involvement, operational involvement, strategic involvement and evaluative involvement (Perkins & Goddard, 2005). This tool aims to help determine the extent of involvement in these four domains without seeing them as necessarily hierarchical (though involvement within each can increase in sophistication). When using the information gathered using this tool in planning an involvement initiative, it is important to bear in mind that the means by which involvement is implemented can be as important as the ends it achieves.

Within each of these domains there can be four levels of involvement (adapted from DoH, 2004):

- Red** Service users and carers have little or no involvement in this area
- Amber** Service users and carers have some involvement but are not equal
- Blue** Service users and carers have equal involvement
- Green** Service users and carers are in charge!

The types of involvement listed below (individual, day-to-day running (operational), service planning (strategic) and feedback (evaluative)) are each as important as each other. The questions below will help you decide the approximate level of involvement (**red**, **amber**, **blue** or **green**) that is currently happening in your service in each of these domains. The colour you select should reflect the usual level of involvement. For example, in 'individual' involvement, if service users and carers are usually involved in deciding goals for therapy (**blue**) and occasionally decide exactly which treatment an individual will receive (**green**), the service would be appropriately coded as 'blue' as that is the most common level of involvement in that service.

Individual Involvement

This refers to having a say in personal treatment, for example, being included in CPA meetings or deciding what to do next in therapy.

Circle the colour that corresponds to the most typical level of involvement service users and carers participate in on an individual level:

Red Service users and carers receive care (e.g. meet with a psychologist) but have no other say (e.g. are not included in care-planning decisions).

Amber Service users and carers can decide between options listed by professionals (e.g. morning or afternoon appointments).

Blue Service users and carers are often included in making decisions about goals for interventions and treatments (e.g. service users and carers state which problem is most important, which becomes the goal for treatment).

Green Service users and carers tend to decide goals for and types of treatment alongside mental health professionals (like blue above but including decisions about which types of treatment are offered, for example, CBT or family therapy).

Day-to-Day running (Operational Involvement)

This means having a say in how the service is run, for example, sitting on interview panels to decide who is employed and other everyday activities.

Circle the colour that most closely resembles the extent of involvement in your service.

Red Service users and carers rarely decide or have no say in decisions about how services are run (e.g. are not invited onto interview panels or to meetings).

Amber Service users and carers are often present when decisions about how services are run are made but do not have equal say in them (e.g. asking a question at interview but not having equal say in who is offered the job or being invited to meetings but not having space on the agenda for their concerns).

Blue Service users and carers have equal say in decisions about how services are run more often than not (e.g. having as much say in who is employed at interview as professionals or being present at meetings with an agenda item but not able to influence the rest of the agenda).

Green Service users and carers usually lead decisions about how services are run (e.g. having the 'casting vote' deciding which skills the successful candidate should have or having space to raise concerns at meetings and which are considered, investigated and reflected in the final decisions made).

Service Planning (Strategic Involvement)

This refers to having a say in how the service overall changes, for example, which new teams to bring together.

Circle the colour that most closely resembles your service.

Red Service users and carers rarely have a say in changes to services.

Amber Service users and carers are often asked what they think about possible changes (e.g. are invited to consultation meetings) but do not have real influence over the decisions made.

Blue Service users' and carers' views are routinely considered and are seen to have some influence over the decisions made by professionals about how services will (or will not) change, for example, proposed changes are amended.

Green Service users and carers usually decide new directions for services (e.g. suggest the changes themselves or have the 'deciding' vote).

Feedback (Evaluative Involvement)

This means service users and carers are routinely asked for views on varied aspects of what the service is like (e.g. questionnaires), decisions are made with this feedback in mind and involvement itself is monitored.

Put a circle around the colour that sounds most like your service.

Red Service users and carers are not usually asked for feedback on their experience of the service they are using or about their involvement (but may be asked more general, isolated questions).

Amber Service users and carers are asked for feedback on the service they use through questions designed by professionals (e.g. questionnaires, surveys) and involvement initiatives are occasionally evaluated.

Blue Service users and carers are usually asked for feedback on the service(s) they use through questions designed with and/or asked by service users and carers (e.g. focus groups lead by service users), involvement initiatives are often evaluated.

Green Service users and carers normally decide which areas should be researched and ask the questions, weigh-up the responses and determine the results (e.g. through 'user-focussed monitoring') with monitoring of involvement being embedded within the organisation.

To map involvement in your service

Transfer the colours you circled above onto the diagram on the next page.

1. Firstly put a cross at the point where the 'Individual Involvement' arrow meets the circle colour that corresponds to the level of 'Individual Involvement' (**red**, **amber**, **blue** or **green**) you noted above.

2. Repeat this process for 'Day-to-Day Running' (Operational), 'Service Planning' (Strategic) and 'Feedback' (Evaluative) involvement.

3. Join the crosses with straight lines to make a four-sided shape. The closer this shape is to the dashed square, the more advanced involvement initiatives seem to be in that service.

Red domains – those closest to the centre of the diagram could be the best places to focus involvement initiatives on next.

It is important to bear in mind that service user and carer involvement occurs within systems and may be construed as non-linear (Tritter & McCallum, 2005), thus the levels of involvement referred to may not capture the accountability, complexity and interdependence of involvement between the four different domains. Process as well as outcome should be attended to.

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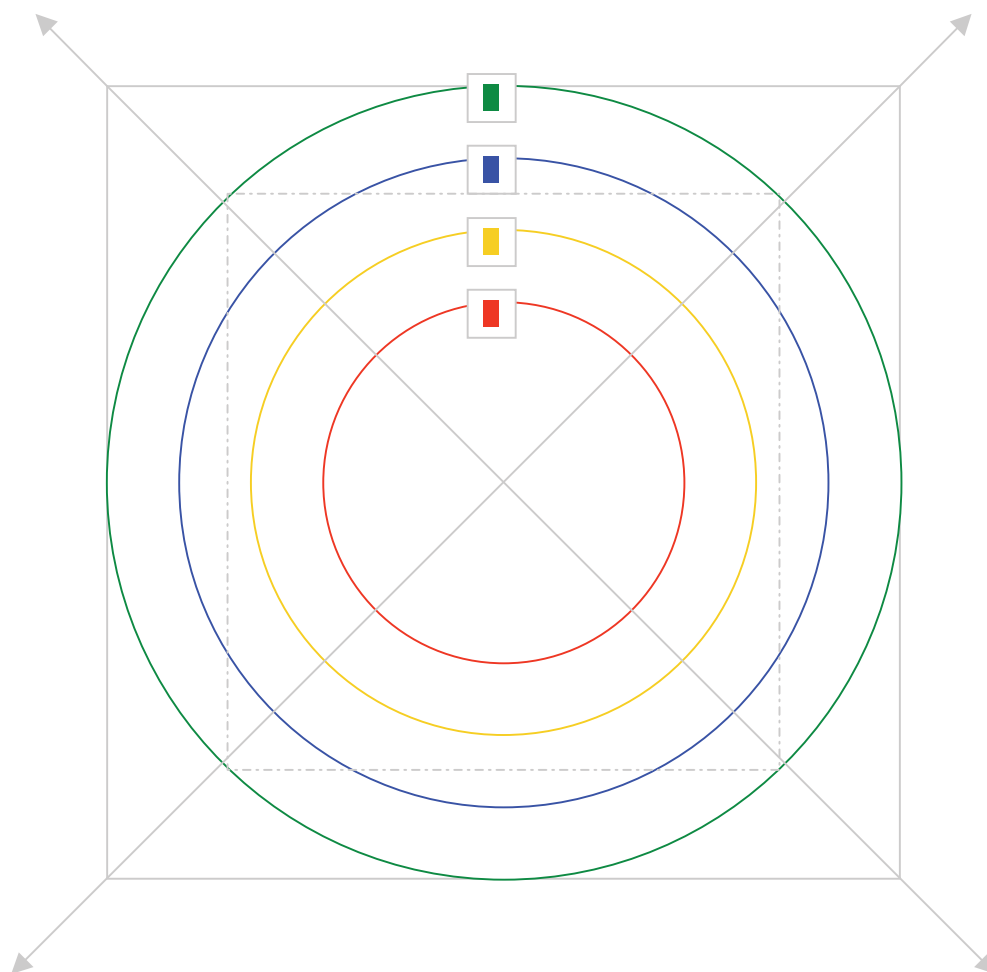
Planning/Mapping Tool

Individual Involvement:

Service users and carers having a say in treatment, for example, being included in CPA meetings, deciding what to do next in therapy.

Day-to-Day Running (Operational) Involvement:

Having a say in how the service is run, for example, sitting on interview panels to decide who is employed.



Service Planning (Strategic) Involvement:

Service users and carers' influence in how the service overall changes, for example, which new teams/functions to bring together.

Feedback (Evaluative Involvement):

Being asked for views on what the service is like (e.g. questionnaires) and the influence of service user and carer priorities.

Appendix B. Planning Proforma

The simple proforma below is intended to assist in the planning of involvement initiatives at service or team level. The headings are intended to guide rather than dictate and can be adapted as needed.

Name of Service/Team:
Question or Focus of the planned initiative including how it was/will be derived:
Key personnel (and mechanism if applicable, e.g. working group) leading, developing and overseeing the planning and their affiliations (e.g. service user, carer, lead clinical psychologist):
Partners/links made/to be forged (other local services, user and carer groups, voluntary orgs, advocacy, academic):
Resources: Funding available; budget; input from PPI team:
Methods (for generating support, collecting/analysing/reporting data):
Support requirements (staff and service users/carers): training; specific needs, for example, for travel, communication; information.
Scope/methods for applying findings and providing feedback:
Mechanism(s) for evaluating involvement: feedback on process/experience; lessons learned for next time; wider learning:

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