SERVICE USER INVOLVEMENT IN THE DELIVERY OF MENTAL HEALTH SERVICES

Service user involvement is about making sure that mental health services, organisations and policies are led and shaped by the people best placed to know what works: people who use mental health services. They are experts by experience.

Increasingly, meaningful involvement of people who use — or have used — services is being recognised as an indispensable part of mental health service delivery. When people are equipped and supported to help commission, deliver and check the services they and their peers use, those services improve and the people involved gain in confidence and skills.

This briefing is for those planning, commissioning, designing and overseeing mental health services, as well as those involved in the development of mental health policy. It aims to give guidance on how to make service user involvement integral to these, as well as signposting to further resources in this area.

> "Service-user leadership is fundamental to designing, delivering and checking services that support people to fulfil their potential. Only by transforming services in the way that the people who use them want us to can better outcomes be achieved at a time of real budget constraint."
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> Dr Geraldine Strathdee, National Clinical Director for Mental Health, NHS England.
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> For a detailed discussion of the value of user involvement and leadership, see *Service user leadership: training and development for service users to take the lead* by A. Newton, A. Beales, D. A. Collins and T. Basset (*Journal of Mental Health Training, Education and Practice*, Vol. 8 No. 3 2013, pp. 134-140)

Defining service user involvement

At its most basic, service user involvement is the active participation of a person with lived experience of mental distress in shaping their personal health plan, based on their knowledge of what works best for them.

As the wider benefits of inclusion have become apparent and recognised, it has also come to mean the active inclusion of the perspectives of service users collectively in the design, commissioning, delivery and evaluation of services, as well as in policy development locally and nationally. This has been the accepted definition for many years, though progress towards achieving genuine service user involvement across the mental health sector has been gradual.

Simple as this principle may seem, it is important to understand the nuances of what is meant by 'involvement' to avoid the term being used to mean other things. In particular, service user involvement is **not** about:

▸ permission-giving, engagement or empowerment by others

▸ patient satisfaction surveys

▸ service users being involved on the terms of providers, commissioners or regulators (ie not on their own terms)

▸ 'single representation' (one-off attendance or involvement, with the responsibility to represent the views of all service users)

▸ over-reliance on the same few people to be the 'user voice' without reference or connection to the wider service user community

Rather, it is about people **asserting** their perspectives and being heard in their own right. It is about being **active**, not passive.

The **National Survivor User Network** (NSUN) is an independent, service-user-led charity that connects people with experience of mental health issues to give us a stronger voice in shaping policy and services. NSUN is a Department of Health strategic partner and member of the Department's ministerial advisory group on the mental health strategy.

Together is a national charity working alongside people with mental health issues on their journey towards independent and fulfilling lives. A recognised leader in service user involvement, Together runs around 80 services across England and believes that people using services are the experts in their own recovery and should direct and shape the support they and others receive.

For the purpose of this briefing, we will define it as:

'service users involving themselves, as individuals and groups, to develop, deliver and evaluate mental health policy and practice.'

Implicit in all of this is a leadership role, either at an individual or group level. By asserting responsibility for their own wellbeing and collectively shaping what is made available to others, service users are actively demonstrating leadership.

Service user involvement has given rise to a number of important related principles such as co-production, peer support and service user leadership (see panel below for definitions).

The following are accepted definitions of some common terms relating to service user involvement:

User leadership means service users have the majority say in decisions at every level (eg a user-led organisation, a user-led training programme).

Lived experience is used to describe someone's own experience of mental distress.

Peer support happens when someone uses their own lived experience to support another person experiencing mental distress.

Co-production is where service users, peer supporters and staff work together as equal partners to design and deliver a service, ensuring that people with lived experience lead the way. This includes development, governance, delivery and evaluation.

"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."

Peter Campbell, service user and long-time activist and campaigner

Service user involvement in mental health policy

This Government's first commitment to service user involvement was expressed in the White Paper *Equity and Excellence: Liberating the NHS* (DH, July 2010), which signified the start of extensive changes to the way the health service operates. The paper stated:

In future, patients and carers will have far more clout and choice in the system; and as a result, the NHS will become more responsive to their needs and wishes. People want choice, and evidence at home and abroad shows that it improves quality.

One of the ways in which service users were to be enabled to have more 'clout and choice' was through co-production, defined by the Department of Health as:

when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered. (PPF Communications toolkit—www.puttingpeoplefirst.org.uk).

In *Practical Approaches to Co-production* (DH, 16 November, 2010) the four steps needed to achieve this are outlined as:

▶ *Target it*—focus on the services and issues where a move to greater co-production is likely to produce the greatest benefits in relation to costs;

▶ *People it*—focus on co-producing with those people who are most likely to achieve high priority benefits at low cost to the public sector, especially where those benefits go to those members of the community in most need;

▶ *Incentivise it*—focus on finding ways to ensure win-win outcomes for all users and members of the community who co-produce with public services;

▶ *Grow it*—focus on finding ways to scale up the co-production initiatives by getting those involved to bring in other people and by promoting its imitation elsewhere.

For a fuller picture of the development of service user involvement in a policy context over the years, see *National Involvement Partnership: Service User Involvement in Policy, NIP Policy Document—Draft Two* (NSUN February 2014).

A few points to note:

The term 'peer-to-peer support' is occasionally used as a response to the misuse of the term 'peer support', for example, when it is used to mean support given by someone without experience of mental distress.

'Leadership' is often understood as something hierarchical that meets the managerial needs of an organisation. In a user-led context, it is understood as a non-hierarchical activity of sharing expertise and life experiences to produce a collectively-agreed way forward. It still relies on individual skills, courage and commitment to drive initiatives forward on the basis of shared values.

Some organisations use other terms interchangeably with 'user-led', for example 'peer-led' or 'client-led'.

This was followed by *No Health without Mental Health: a cross government mental health outcomes strategy for people of all ages* (DH, February 2011), which made explicit references to the value of encouraging service user involvement:

[…] local voluntary and community organisations can draw on the wealth of experience of their local communities in meeting the needs of groups they work with, including those groups most excluded and/or experiencing poor mental health. Some of these organisations have experience of helping people to manage their own mental health better in the community—including through peer support services, user-led self-help groups, mentoring and befriending, and time-banking schemes, which enable service users to be both providers and recipients of support. Well managed and well-supported volunteering opportunities can help people to develop the skills and confidence to play a more active role in their own wellbeing and their community, and to influence the shape and scope of local services. Innovative approaches aimed at involving service users and the wider community can also help to break down barriers and reduce stigma. (p. 35)

The Francis Report (Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, February 2013) emphasised the need to place the patient at the centre of healthcare throughout the NHS.

Service user involvement in practice

More than 200 regular inpatients of South London and Maudsley NHS Foundation Trust have been helped to settle permanently in the community thanks to changes made by the Lambeth Living Well Collaborative, which gives mental health service users an equal voice with commissioners and providers.

In Hackney, NSUN has helped build a 'people's network' of mental health service-users to get involved in commissioning, delivering and scrutinising services. These peers have already helped re-write the East London NHS Foundation Trust care pathway. In Leicester, Suffolk, Lambeth and Newcastle NSUN is working with local partners to develop similar peer-support and involvement networks.

Turning Point's Connected Care system of enabling communities to design their services has been evaluated by a London School of Economics Social Return on Investment (SROI) study to save over £14 for every £1 spent.

Well London's Health Champion programme involving 2,000 people making decisions about services for themselves resulted in 79 per cent feeling more positive about their life and having a better understanding of their mental wellbeing, 82 per cent making healthier eating choices and 85 per cent taking more exercise.

The service user led Changing Minds programme was found by an East London University SROI to save £8.78 for every £1 spent.

Putting Patients First: The NHS England business plan for 2013/14–2015/16 states:

High quality, clinically-led commissioning will be a mainstay of the new healthcare system. Commissioning will focus on issues that matter locally, underpinned by robust public and patient involvement. We will stand alongside CCGs as commissioners of healthcare services, and provide the leadership and support to help them to become excellent commissioners. (p. 11)

In summary, current mental health policy demonstrates a commitment to making service user involvement an intrinsic and essential component of service delivery. Progress towards achieving this has largely been testament to the work of service user groups, voluntary organisations and academic institutions. But there is a huge amount still to be done to ensure the principle of involvement is applied across the board, and that this involvement is genuine and constructive.

For service users to involve themselves meaningfully in a service or organisation, the environment, mindset and frameworks all need to facilitate this. This is perhaps the most important role for someone designing, implementing or overseeing a service.

A great deal of work has been done to develop quality standards for user involvement. NSUN's National Involvement Partnership (NIP) Project aims to 'hard wire' the voice of service users and carers into health and care services. The NIP Project has developed national standards to provide a simple yet robust framework for good practice, and to measure, monitor and evaluate involvement. *See 4PI National Standards* (NSUN, 2013)]

How to embed genuine service user involvement
Becoming an organisation or service that involves service users meaningfully is — like most organisational change — something that happens gradually.

It can require (often subtle) changes in many areas of an organisation or service, including HR, finance and governance, and takes ongoing commitment and monitoring to maintain progress. Often the hardest thing is to set the ball rolling in the first place.

To begin embedding, improving and maintaining service user involvement, it is helpful to first understand what stage your organisation or service is at. The diagram on page 5 is designed to help with this, as well as to give an idea of what activities and approaches constitute genuine service user involvement.

To operate at the most useful level, service users need to be supported to gain knowledge, skills, confidence and leadership. One of the best ways of progressing is to contact and learn from organisations that have already made good progress in successfully implementing service user involvement. Several organisations also provide training for both service users and organisations (see page 6 for details).

Training and consultancy
Together offers practical training for people wanting to become peer supporters, as well as consultancy for organisations wanting to implement service user involvement. It also hosts the Peer 2 Peer network, which facilitates the exchange of good practice in peer support between service user groups, voluntary organisations, statutory service providers and commissioners.

NSUN has delivered three Leadership Programmes in the South East, London and Leicestershire. Participants continue to meet, agree collective action around agreed service issues, provide mutual support and promote the value and 'living evidence' of the potential that involvement and leadership has. A graduate from the London Leadership programme co-designed and delivered the Leicestershire Leadership programme.

Introducing peer support in West Sussex

When Sussex Partnership NHS Foundation Trust first got in touch with the Capital Project Trust in 2009, they were looking to add value to the experience of their patients with mental health needs. As a peer-led organisation specialising in promoting and delivering peer support, the Capital Project Trust was well-placed to advise, and its first task was to write the brief from scratch. This non-prescriptive approach was essential to ensure that people with experience of mental distress led the way from the outset. The plan set out measures to embed a mix of one-to-one and group peer support, ensuring there were enough peers on the hospital sites at any one time to also support each other. Capital already had experience of working with other hospitals locally so they had a good idea of what would and wouldn't work, but the brief and ongoing development of the initiative with Sussex Partnership was devised to fit their specific ways of working and protocols. This meant that peer support could become an integral part of their care rather than a stand-alone add-on delivered by a third party.

There are now eight substantive peer supporter posts at three hospital sites in West Sussex, as well as a bank of additional peer supporters in case they are needed.

Setting this up required continuous reflection on progress and a flexible approach from both organisations. Clare Ockwell from Capital Project Trust says: "There was a lot of enthusiasm from the very beginning at Sussex Partnership Trust, and we worked closely with ward staff to see how this new element of support would fit in with their day to day working. Once this preparatory work was done and the peers started actually giving support, their value was self-evident—we had so much good feedback from both staff and those being supported.

Introducing peer support is a different process in each organisation, and close joint working is essential. Both organisations talked throughout the process, and sometimes suggestions and ideas needed to change or give way to others. This made it a truly joint initiative, which was crucial for its continued success, but it was also led throughout by people with experience of mental distress and the importance of this can't be underestimated. It can sometimes be unnerving for professionals to yield the control necessary for this to happen, but the results of user leadership speak for themselves."

More case studies can be found in *Guidance for implementing values-based commissioning in mental health* (Joint Commissioning Panel for Mental Health, pages 13-19.)

Involving service users when a service changes hands

When Together won a contract to run floating community support across Norfolk, we knew we needed to make service user involvement integral to the service from the outset. We drew on the expertise of colleagues in our Service User Involvement Directorate, working hand in hand with them to make sure involvement was at the forefront of our minds at every stage and implemented jointly with them on the ground.

At the moment we started talking to staff about the change process, we were also consulting with those accessing the service and ensuring that they led this process. We held information sessions for both staff and service users, inviting all involved to talk openly about the change process and future of the service. These sessions were led by people with lived experience and a key aim was to understand the specific needs and wishes of those that would be using the service. In addition, people with lived experience were on the recruitment panels for interviews with new and transferring staff, and a peer support coordinator was recruited to lead the process of making peer support integral to the new service.

Our Involvement to Leadership training developed people's skills and confidence to lead change and decisions about the service. Service users will form part of the team responsible for monitoring and evaluating the service, and communicating this back to the commissioners. We are also convening a management council with a majority of members with lived experience, to lead key decisions about the direction the service takes.

Cashain David, Together's Operational Director responsible for the service in Norfolk, comments:

"It's important to understand that service user involvement isn't something that happens overnight – nor can it be achieved by just a small handful of people. It requires organisational and cultural change that is often more far reaching than people expect.

One of the most difficult things is to resist the temptation to hold on too tightly to your implementation plan. For service users to lead the way, you need to let go, spend time listening and trust the people leading the process. There are no shortcuts or set formulas – each case will look different and require a different approach. In this case, the information sessions in particular let us tap into really valuable 'insider information' from those using the service. We couldn't have got this perspective any other way, and it undoubtedly made the service more adapted to the local need.

Dealing with change can be a difficult process, and it's even more important to get service user involvement right when there is uncertainty or anxiety about changes to support. The changes to the service in Norfolk were an excellent opportunity to reflect on practices and really embed the right culture and structures to be successful in involving the people that matter most: those using the service."

WHERE DO YOU FIT ON THE SERVICE USER LEADERSHIP SPECTRUM?

WHAT DOES YOUR ORGANISATION DO TO SUPPORT SERVICE USER LEADERSHIP?

Beginnings of service user involvement

- Service user consultation via:

  — *Surveys*
  — *Service users attending staff meetings to feed back information collected*
  — *Meetings between staff and service users with no formal agenda and no time to plan*
  — *Service users attending meetings where the agenda is set by the organisation*

- Staff not required to act on service user feedback

- Quality measures use clinical standards only

- Staff training content contains no service user input

- Priorities determined by systems, rather than people

- Leadership and vision is seen as the domain of staff

Good service user involvement

- Independent service user perspectives present at all levels of the organisation

- Service users influence governance, policy and practice of the organisation

- Internally, service users lead some initiatives through to completion

- Externally, service users originate and lead some organisational initiatives with minimum influence from the organisation

- Service user groups preparing to become independent of host organisation

- Organisation remains responsive to service user leadership even if it doesn't plan to become service user led

- Pro-actively building local service user led organisations and initiatives (may include capacity building for a national infrastructure to support this)

Service user led

- Service users lead on governance

- Service users lead on authentic peer support

- Service users articulate and measure quality of practice and service outcomes

- Service users lead policy development

- Contributes to capacity building of service user led groups and development of a national infrastructure to support this

- Supports independent service user led groups

- Can host service user led initiatives through to independence

- Leadership and vision owned by people who access mental health services and carers, as well as professionals and staff

- Community-based or 'of the community'

- Co-production is service user led around agreed, shared agenda

→ → → → IMPLICATIONS: *Where are you on the spectrum?* → → → →

Beginnings of service user involvement

Good service user involvement

Service user led

In summary

1. Service user involvement needs to be an integral part of mental health services and organisations for them to be truly effective.

2. Genuine service user involvement is about service users involving themselves — beware of the term being used to mean other things.

3. Organisations can and should support and guide each other to successfully implement genuine service user involvement.

4. Becoming an organisation that involves service users meaningfully is about making changes in a whole range of areas. Track your progress using the grid on page 5.

5. There are resources on hand to help — see right for details of useful organisations.

For further information and advice, contact:

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