Service User Involvement in Collaborative Care

1. Learning Outcomes

Welcome to this e-lecture on service user involvement in collaborative care. User involvement in health and social care policy and practice has been gaining emphasis over the last decade.

Health and social care services are more likely to deliver better quality care and experience, if health and social care professionals receive education and training that has been designed, delivered and quality assured with the involvement of patients and the wider public.

‘Patient involvement means more than simply engaging people in a discussion about services. Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper’

A Promise to Learn, A Commitment to Act, (August 2013)

With the help of Service Users this Sheffield Hallam University has recently developed a policy called Experts By Experience - Reward and recognition guidelines for services user and carer engagement (May 2014)

The Learning outcomes for this e-Lecture are:

- What is Service user involvement and why is it important?
- Levels of service user involvement
- Roles of professionals in service user involvement
- Challenges involved in service user involvement

2. Political and Government agendas that have driven development of Service user involvement in Health and Social Care

High on the Government Political agenda is service user involvement in driving policy and improvement of services. (Putting people first, A promise to learn, the NHS constitution etc)

The drive towards user involvement in health and social services emerges from a number of strands that can be traced over almost three decades. See 'References'.

This initiative was intended to put into the forefront the kind of standards of public service that people had a right to expect (Waldegrave, 1996). The NHS contribution to the Citizens’ Charter was realised through The Patients’ Charter (DoH, 1991) in which the philosophy of ‘rights’ to service was continued. The Patients’ Charter was designed to transform traditional conceptualisations of the NHS patient as a passive recipient of what the health service had to offer to that of a discerning customer of the service.

Empowerment is also a powerful concept influencing the service user involvement movement with the United Nations (1995:12) placing emphasis on participation being a vehicle for empowerment stating that “developments must be by the people, not only on them”. This value can be traced in government publications such as ‘Nothing about us, without us’ (2000) and ‘Putting People First’ (2007).
A Promise to Learn, A Commitment to Act, highlighted that ‘Patient involvement means more than simply engaging people in a discussion about services. Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper’

A Promise to Learn, A Commitment to Act, (August 2013)

(Adapted from Gordon et al, 2004).

3. Recent policy and links to service user involvement and collaborative care

The collaborative emphasis: Recent policy has emphasised joined up care concerning cross-working and partnership across health and social care services. Interprofessional, inter-organisational and interagency collaborative practice is seen vital to the provision of high quality care for service users and their carers. The input of service users to the planning of services and care and their evaluation of their experience of services are key aspects.

The 'Our health, our care, our say' White paper developed by the new Labour government was the result of two major consultation exercises involving thousands of members of the public and its aim was to confirm the vision in a green paper called "Independence, wellbeing and choice" emphasising high quality support, meeting people’s aspirations for independence and greater control over their lives. The findings of these strategic level public involvement activities were used to inform subsequent government direction for the NHS and social care services. The main thrust of the policy was to emphasise patient and service user choice and involvement in decision making and the provision of joined up care across health and community and social services.

Our health, our care, our say set out government policy regarding the public’s wishes for easier access to services including: rapid access to GPs and the provision of extended opening hours; more personalised mental health services with increased access to ‘talking therapies’; the decentralisation of large hospitals bringing care back into communities and linking more closely with social care; the provision of better information; improving health with local support for maintaining healthy lifestyles; care for people with ongoing needs including the introduction of individual budgets to give people more control of the type of social care they received, help for carers; and attention to health and social services sharing information and delivering ‘joined up care. The aim of Our health, our care, our say was to give people more say and more choice about the services they received. It carried a mandate that all organisations providing health and social care services were expected to seek the views of patients and service users, act on these views an involve local people in decision making

Equity and Excellence: Liberating the NHS
The coming of a new coalition government in May 2010 saw the release of a new white paper Equity and Excellence: liberating the NHS, echoing previous policy around service user involvement and patient power, although detail of how this would be implemented was not yet fully determined. This paper indicated that patients will be at the heart of everything the government intended for health and social care.
Shared decision making is a central theme of *Equity and Excellence: liberating the NHS* with direct reference to the previous government’s policies through its phrase "no decision about me without me" (DoH, 2010:6). Joining up of local NHS, social care and health improvement services to improve the service user experience was a recurrent theme. Again re-emphasised from previous policy, was people being able to make choices and be involved in evaluating the care they receive. The collective voice of patients and the public would be heard through a consumer champion on the care quality commission giving citizens a greater say on how the NHS is run.

It can be seen that policy of the last UK government and re-emphasised by the current, has continued the emphasis of patient and service user involvement in the services they access. This has concentrated on users of services being able to influence how services are designed, for example having care provided more locally and providers being required to collect and act on feedback. Another main and related issue is patients and service users being able to exercise choice about the care they receive and that this care is ‘joined up’ across health and social care. It can be argued that in order to deliver on this agenda of choice and control for service users, collaboration across teams, services, agencies and organisations continues to be pivotal to delivering on the strategic direction of health and social care services.

4. Why service user involvement is important

The Public Administration Select committee report on User Involvement in Public Services (2007-8) drew on evidence to discuss how the design and delivery of public services could be improved by involving the people who use them. Several issues were identified including:

**The moral imperative**
The moral right to self-determination suggests that people be involved in discussions with care providers to enable them to exercise choice and have the autonomy to make their own decisions. At the level of day to day practice, this infers that service users and their carers may need help to understand the issues at hand to enable autonomous decision making. In turn, service users and carers must be consulted and listened to and if necessary helped to explain their needs and priorities.

**Part of a healthy democracy**
It is argued that public involvement in policy development including consultation with and the use of feedback from people who use public services is part of a healthy democracy and can assist in the improvement of public services and where responsive to need can improve satisfaction with services. People are empowered through being able to shape services that affect the quality of their own lives. The downside of this is the difficulty of ‘representative democracy’ in that ‘user power’ of a minority can carry the risk of diverging from policy set by elected representatives.

**Improving public services**
Proponents of user participation in public services claim that it reduces the risk of the development of inappropriate or unsuitable services. User involvement can help people better understand their own service needs and therefore improve health or educational progress. User involvement can translate into improved service delivery and higher satisfaction rates, these are likely to translate into better service outcomes. However, the evidence that these assertions are based on are from small pilot schemes with enthusiastic and well informed users. Care needs to be taken in translating these findings to wider, larger scale involvement.
Cost effectiveness and value for money
The evidence around whether user-driven services are more or less cost effective is ambiguous and scant. Proponents claim that individual or personal budgets where people are determining their own requirements can cost less than other forms of provision but in other circumstances it will be more expensive to tailor care around an individual.

(Taken from User Involvement in Public Services, Public Administration Select Committee, 2008)

5. Levels of Service User Involvement

Patient involvement means more than simply engaging people in a discussion about services.

Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper.

A Promise to Learn, A Commitment to Act, (August 2013)

How people get involved is hugely variable and ranges from individuals simply making choices regarding their care at service level provision, to being part of user-led community development work, to being members and governors of NHS Foundation Trusts; to being part of patient activist and/or self help groups to sitting on policy making boards in government departments and involvement in parliamentary lobbying.

There has been some disquiet expressed regarding how meaningful, inclusive and participative service user involvement can be. Carr (2004) has warned of a number of barriers to meaningful involvement including professional resistance; poor conflict resolution between professionals or service users/carers and professionals and exclusive practices that marginalise the involvement of certain minority groups. She also identifies how the type of involvement that is promoted can limit the level of change that is being sought through the involvement agenda.

Carr (2004) indicates the importance of ensuring that service users participate at the level they feel comfortable and that it is important that participation is enabled through ensuring accessibility measures, training and information giving where necessary.

There has been some disquiet expressed regarding how meaningful, inclusive and participative service user involvement can be, in addition to how vulnerable and comfortably they feel. Carr (2004) as a result of this guidance has been developed:

- Core Principles of Involvement Skills for Care and The Commission of Social Care Inspection (England) as well as the General Social Care Council and Social Care Institute of Excellence (UK)
- Ladder of Participation Best practice guide - serviceuserinvolvement.co.uk
Core principles of involvement of Service users:

There should be:

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<th>Principle</th>
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<td>A clear reason and purpose for engagement, using principles of shared decision making between staff, students and the public</td>
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<td>Appropriate engagement in education and research with people who use health and social care services, agreeing flexible ways in which people can contribute</td>
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<td>Clear responsibility and accountability agreed through partnership working to develop priorities through shared decision making</td>
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<td>Value and recognition for the contribution of all stakeholders</td>
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<td>Informed changes using what we have learnt through the engagement of staff, learners and experts by experience to influence changes in our ways of working to achieve better outcomes</td>
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<td>Harnessing the potential for people to be involved, by identifying and overcoming any barriers to involvement</td>
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Table 1. Principles of engagement adapted from the previous work by Skills for Care and The Commission of Social Care Inspection (England) as well as the General Social Care Council and Social Care Institute of Excellence (UK)

Ladder of Participation

The Ladder of Participation is a model that can be used to examine where you are in terms of service user involvement now and where you want to be in the future:

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<tr>
<td>FULL CONTROL:</td>
<td>Service users control decision making at the highest level</td>
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<td>SHARING POWER:</td>
<td>Service users share decisions and responsibility, influencing and determining outcomes</td>
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<td>PARTICIPATION:</td>
<td>Service users can make suggestions and influence outcomes</td>
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<tr>
<td>CONSULTATION:</td>
<td>Service users are asked what they think but have limited influence</td>
</tr>
<tr>
<td>INFORMATION:</td>
<td>Services users are told what is happening but have no influence</td>
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<tr>
<td>NO CONTROL:</td>
<td>Service users are passive consumers</td>
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6. Role of professionals in promoting involvement (no change to slide or Voiceover)

Clearly service user involvement occurs at multiple levels and in diverse ways. It can be challenging, particularly for vulnerable people, and most people becoming involved will have at least information needs. Leadbeater and Cottam (2007) have identified a number of roles that professionals can take in order to promote meaningful involvement.

**Advisors**
The advisory role is about helping users to assess their own needs and to participate in making plans for their future care.

**Navigators**
The navigation role is about helping users find their way to the services they require.

**Brokers**
The broker role is about helping users assemble a package of care or services that meet their needs, particularly where specific services come from different sources.

**Service providers**
The service provider role is concerned with directly providing care or a service.

**Risk assessors and auditors**
The risk assessment and auditor role is particularly concerned with assisting vulnerable people to identify and assess risks that may arise.

(Leadbeater and Cottam, 2007)

7. Conclusions

- Service user involvement continues to evolve is based on: increasing levels of lay knowledge; a consumerist value base, rights to self determination and empowerment.

- Recent government and Political agendas emphasis and have pointed to collaborative practices and service user involvement as being the key to delivering effective health and social care services.

- The importance of service user involvement is determined by the concepts of moral rights, democracy, improvement of services and value for money.

- User involvement faces a number of issues, including how ‘representative’ user groups might be and the challenge they may pose to democratically elected decision makers. The voices of minority groups are sometimes marginalized or difficult to elicit. Meaningful involvement is subject to adequate support and education, particularly among vulnerable groups.
• The level of involvement is hugely diverse. People should be encouraged to be involved at levels they are comfortable with but at the same time be empowered through information, training and other support to get to the level of involvement to which they may aspire.

• Professionals can take on a number of roles to promote involvement.

8. References

Policy:
NMC (2010): Standards for pre-registration nursing education

Legislation:
2009 no. 2655 The social security (miscellaneous amendments) (no. 4) regulations 2009.
2009 no. 2678 The social security benefit (computation of earnings) (amendment) regulations 2009.
2009 no. 2608 The housing benefit and council tax benefit (miscellaneous amendments) regulations 2009.

Guidance and Resources:
Housing Benefit and Council Tax Benefit circular
Equality impact assessment changes to the way DWP deal with payments to ‘service users’ published by
Benefit Reform Division, Welfare and Wellbeing Group.

Bibliography for further reading:


Boyle, D., Harris, M. (2009) The Challenge of Co-Production: how equal partnerships between patients and the public are crucial to improving public services’ NESTA


Department of Health (2010) Practical Approaches to Co-production: building effective partnerships with people using services, carers, families and citizens


The NHS Confederation (2008) Principles for Accountability: putting the public at the heart of the NHS

The Health Foundation (February 2012) MAGIC: Making Good Decisions in Collaboration