

# Informed, involved and influential: three Is of shared decision making

Gemma Stacey and colleagues describe how service users can improve their levels of freedom through close collaboration with mental health professionals

## Correspondence

gemma.stacey@nottingham.ac.uk

Gemma Stacey is an assistant professor in mental health at the School of Health Sciences

Anne Felton is an assistant professor

Ada Hui is a teaching and research associate

Theo Stickley is an associate professor

All at the University of Nottingham

Philip Houghton is a clinical psychologist

Bob Diamond is a clinical psychologist

Both at Nottinghamshire Healthcare NHS Trust

Alastair Morgan is a senior lecturer at Sheffield Hallam University

James Shutt is an advocate at Pohwer Advocacy, Nottingham

Martin Willis is a research student at Loughborough University

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## Abstract

Collaboration between service users and mental health professionals is at the heart of values-based practice and shared decision making. However, there has been limited analysis of the implications of these approaches to processes that can involve depriving service users of their freedom. This article proposes a framework in which it is acknowledged that all participants must be informed, involved and influential in the decision-making process. The article notes, however, that these aims are on a sliding scale of influence that depends on context, capacity and desire to influence.

## Keywords

shared decision making, power, values based practice, mental health, influence

THE SERVICE user movement and consumerist models of health care have significantly changed the perception of the role of patients in their own care. This change has culminated in a policy framework that enshrines patients' choices at the heart of health care (Department of Health 2012). The Mental Health Act 1983: Code of Practice (Department of Health 2015), for example, states that 'patients should be fully involved in decisions about care, support and treatment', and that the 'views of families, carers and others, should be fully considered when taking decisions.'

Most mental health care professionals recognise that decisions taken in their practices are based on personal and professional values, as well as on the research evidence (Woodbridge and Fulford 2005). Decision making therefore involves incorporating

the differing and sometimes conflicting values of people involved in planning and delivering services, including service users and carers (Cleary 2003). However, despite the rhetoric about shared decision making in mental health settings, service users remain on the periphery of decision-making processes.

This article summarises the findings of a research study of the barriers to shared decision making in inpatient mental health settings. These barriers arise due to differences in power and perceived accountability among professionals, service users and carers, which can influence opportunities for dialogue about decision making. The article also offers an alternative framework to promote shared decision making.

The role of mental health services in containing and controlling service users is set out in legislation (Szmukler and Holloway 2001). This role may appear to contradict the values on which shared decision making is based. The liberty of people who use mental health services can be affected if they are held in hospital and treated against their will, or if they experience coercion. For example, service users may not perceive decisions to be admitted to hospital as voluntary, even though legally they are (Laurence 2003, Vassilev and Pilgrim 2007, Katsakou *et al* 2010). This means that professionals have, or are perceived to have, the power to override service users' preferences, and people with mental health problems may be aware of this when they use services.

It would be naïve to assume that this gulf in power would not influence the dynamic of negotiation and agreement at the heart of shared decisions. There is little analysis of this influence in

the literature on shared decision making and mental health (Houghton and Diamond 2010).

Shared decision making in mental health practice involves valuing and responding to an individuals' values, social context, preferences and expertise to promote person-centred care and recovery. Like established models of participation, such as Arnstein's (1969), it is based on the premise that the people most affected by the outcomes of decisions should be most influential in making them. However, shared decision making should not be accepted uncritically if it fails to account for issues of power, hierarchy and legally sanctioned coercive practice. Awareness of the complexities in implementing shared decision making in mental health settings is therefore an important step towards enabling more equal power relationships.

### Research study

The authors conducted a research study of the concept of shared decision making in mental health acute inpatient settings. It was achieved by facilitating focus groups of service users ( $n=6$ ), carers ( $n=6$ ), occupational therapists ( $n=5$ ), social workers ( $n=6$ ), peer support workers ( $n=6$ ), psychiatrists ( $n=7$ ) and nurses ( $n=6$ ), with each group made up of people with the same professional or personal background. The focus groups offered insights into their experiences of the decision-making processes, including the degree to which they felt involved in them and could influence their outcomes. Ethical approval to conduct the study was acquired through the National Health Service's National Research Ethics Service.

Data from the focus groups were underwent critical narrative analysis (Landridge 2007), which combines phenomenologically informed narrative methods with critical theory. As a phenomenological method, this form of analysis respects individual subjectivity and takes people's narratives about their experiences seriously; as a critical method, it applies the political critique that people speak from a specific tradition or ideological position to 'destabilise' their narratives. In critical narrative analysis these approaches are not regarded as incompatible or mutually exclusive, but as mutually informing. By adopting this form of analysis, the authors could explore how participants experience decision-making processes, and how issues of power and interest are at play in those processes.

Interpretation of the data involved a six-stage process advocated by Landridge (2007), which attends to how groups position themselves in relation to decision making and the respective

identities that they adopt. Analysis was initiated by the two members of the research team who conducted the relevant focus group. A paper was prepared in which narratives relevant to the research aims were extracted and suggestions about how these could be interpreted from a critical perspective were made. The paper was then discussed and explored by the full research team through a process known as 'destabilisation'. This enabled the synthesis of the following themes.

### Summary of findings

**Service users** On the whole, service users were highly critical of their lack of involvement in decision-making forums that concerned their freedom. They discussed the levels of inclusion they preferred at different phases of their contact with mental health services. They also recognised the need to appear to conform to the outcomes of decisions with which they did not agree so that they could achieve the results they desired, such as getting leave from the ward under section 17 of the Mental Health Act leave or appeals against sections.

**Carers** Positioning themselves outside the decision-making process, carers thought that their knowledge of service users was often disregarded. They thought that professionals used standards or structures, such as confidentiality, to exclude them from decision-making forums and from informing them about the outcomes of decisions. These findings were especially relevant to carers named as the service users' nearest relatives, who had been involved in initial decisions to detain their family members.

**Occupational therapists** Strongly aligning themselves with service users, occupational therapists thought other professionals were sidelining them and reducing their levels of influence in decision-making processes. While they were clear that their area of expertise is occupational assessments and promoting recovery, they did not think these areas were valued by other professionals considering, for example, the risks associated with section 17 leave from the ward.

**Social workers** In viewing their role as approved mental health practitioners, social workers thought they had a legitimised and outwardly respected position when decisions about compulsory care were being made. In routine decision making in wards, however, they viewed themselves as outsiders who were, at best, informed about the outcomes of decisions, but were rarely consulted in the process,

despite their knowledge of legal frameworks and their commitment to a social model of care.

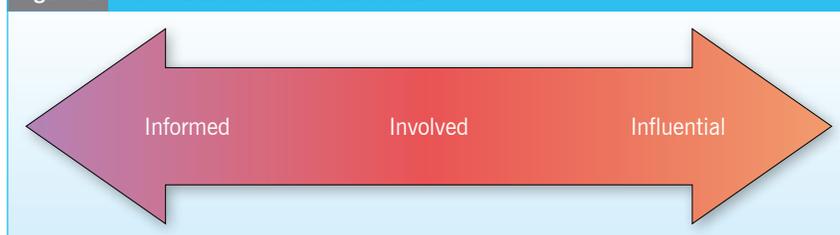
**Peer support workers** Being employed by organisations while attempting to advocate for service users, peer support workers perceived themselves as having an often conflicting role but no voice in decision-making forums. They were clear that their expertise lies in sharing experiences of mental distress, but that no structures were in place to use or respect this expertise in the decision-making process. This lack of structure affected all decisions, but particularly those concerning compulsory care.

**Psychiatrists** Although psychiatrists try to involve other professionals in decision-making processes, they said they are relied on to make definitive decisions, particularly decisions concerning risk such as observation levels and permission to grant leave. They recognised that their roles in decision making are influenced by their education and social position, and that other professionals expect psychiatrists to take responsibility for the outcome of decisions, even those within their professional remit, because of the psychiatrists' salary.

**Nurses** On the whole, nurses viewed themselves as the enforcers of the decisions made by other professional groups, most significantly psychiatrists. For example, when section 17 leave had been revoked, nurses had to prevent the person concerned from leaving the ward, which resulted in physical restraint. They reiterated that, as the professional group that spent most time with service users, they had expertise. Nurses also discussed their lack of willingness to make decisions that they perceive to be the responsibility of psychiatrists, even when it was acknowledged that they may be in the most informed position to make the decision. This was due to the level of accountability they associated with the psychiatrists' role and that they were not willing to take on.

**All groups** Members of all focus groups recognised that the system does not facilitate genuinely shared decision making, especially those that concern compulsory treatment. Each group had its own respective values, but each was positioned as being relatively powerless in changing the system to make shared decision making authentic. It was evident that power hierarchies exist and have significant effects on people within the organisational structure. The 'No decision about me without me' framework (Department of Health (DH) 2012) requires that a fair

Figure 1 The Three Is Scale of Influence



rationale for not involving service users in shared decision making should be given. None of the groups offered an alternative model that would underpin shared decision making, which suggests that the current structures may blind those participating in them to see new ways of working.

### Alternative model

The process of destabilisation uncovered a significant level of cultural practice that was accepted and, in many cases, maintained by group members who gain security from the protection offered by the current hierarchy.

In light of these findings the authors devised a shared decision-making model in which hierarchies and the effects of power are acknowledged to promote a radical level of transparency in the decision-making process. Adopting such a model would require a shift in culture, and would have to be supported by multi-disciplinary clinical supervision and an alternative structure or forum for decisions. In devising the model the authors realised that it is important for professional groups to maintain their professional identities in healthcare settings, but also to talk about these identities in multidisciplinary groups, and to acknowledge uncertainties of role and identity when the power to decide is shared among professional groups, service users and carers.

The authors suggest that the concept of shared decision making should be broken into its component parts. For this to occur, all participants must be informed, involved and influential – three Is – in the decision-making process. These three Is are fluid in that they refer to a sliding scale of influence that moves between different positions according to context, capacity and desire to influence. Thus the model is called the Three Is Scale of Influence (Figure 1)

The model draws on established theories of participation (Arnstein 1969) that recognise how the distribution of power results in a ladder of participation ranging from non-participation, which is viewed as manipulation, to involvement, which can encompass consultancy but can also be regarded as tokenism.

Full participation is achieved, therefore, when there is a genuine power-sharing partnership (Arnstein 1969).

**Informed** Being informed refers to the practice of ensuring that service users, carers and professionals know what is available for consideration. This does not mean that professionals are assumed to know all the options, but that they have valid information to bring to the decision-making process. Nor does it mean that service users are simply told the outcomes of decisions.

People experiencing mental health problems have insights into, for example, the distress that such problems can cause, how they affect their sense of identity and relationships, and how other people view them. They may also have insights into the stigma that is associated with their conditions and what it feels like to live with their diagnoses.

Healthcare professionals rarely have such expertise unless they have had their own experiences of mental distress. However, they do have expertise in, for example, different treatment options, services and resources, and insights into the structure and organisational culture of health services, that are unavailable to service users or other professionals. Being informed entails genuinely valuing the significance of all information and having an understanding of the rationale for decisions.

**Involved** Being involved entails being willing to adapt decisions in light of the information shared. Thus, all parties to decision-making processes should respond to the expertise of others to reach decisions. Traditionally, involvement has entailed consultation with service users and carers. Research shows, however, that consultation does not translate into power sharing, and that professionals' views tend to prevail (Schauer *et al* 2007).

In recovery and shared decision making, the expertise of service users and carers is valued (Deegan and Drake 2006), and service users are regarded as active participants in their own care.

The problem with traditional forms of involvement is that the power to decide when and how service users are involved in decisions lies with the professionals. This may be valid in situations where service users cannot make decisions, but decision-making abilities are often fluid and it should not be assumed that a person is permanently irrational or incompetent, and therefore can never be trusted (Olsen 2003). Generally, people with mental health problems want to be involved in decision making (Matthias *et al* 2012) and, if healthcare professionals question their abilities to be involved because of, for example, their lack of cognitive ability or paranoia, they may prevent service users from communicating their views (Chong *et al* 2013).

An alternative conceptualisation of involvement would concern how service users involve professionals, rather than the other way around. One example of this process is direct payments. These are based on assessments of needs but with service users choosing who provides the services required to meet these needs. If this process were applied to decision-making forums, service users would set the agenda and decide on which experts to consult.

For professional groups, being involved means having opportunities to contribute their views and to be included in collaborative processes. It encourages professionals with different views to be confident in offering them and people who perceive themselves to be outside decision making processes to come inside, while those viewed as being in control of making decisions become open to the views of others.

**Influential** Being influential in decision making entails considering and respecting other people's views, even if they are not held by the majority. For service users, having influence means genuinely holding power and accountability for decisions. This may challenge healthcare professionals to support service users' choices that are perceived as risky or 'bad'.

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In mental health services, emphasising risk can undermine individual choice. Service users are often perceived to need protection from succumbing to their irrational urges and becoming threats to the public (Adams and Drake 2006), yet people without mental health problems have greater autonomy to make choices, including bad ones.

Service users in distress may perceive compulsory care as a preferred option even though it limits their opportunities to influence decision-making processes. In these circumstances, they should be confident that their opinions are respected, and that they will remain informed and involved wherever possible, for example through the involvement of advocates. Service users involved in the authors' study said that this means that compulsory treatment is carried out in a compassionate and ethical manner.

Psychiatrists involved in the study viewed themselves, and were viewed by members of other professional groups, as the most influential people involved in decision-making processes. In the Three Is model, however, all people who contribute to these processes can and should be influential. This does not necessarily mean there is equality of power in but that, where there is conflict, all participants would have opportunities to influence decisions. It also means that the people involved are defined by their relationships with the service users, not their positions in a hierarchy. The informed and involved phases of the Three Is model suggest that service users who are not directly involved in such processes are best placed to decide who should speak for them.

## Implementing the Code of Practice

The Three Is model may go some way towards supporting implementation of the recently revised Mental Health Act 1983: Code of Practice, which states that 'patients should be engaged in the processes of reaching decisions which affect their care and treatment' and that 'carers, [nearest relatives and advocates] are key partners with health and care services and local authorities' (DH 2015).

According to the code's five principles, professionals should ensure:

- The least restrictive option and maximising [of] independence.
- Empowerment and involvement.
- Respect and dignity.
- Purpose and effectiveness.
- Efficiency and equity.

The Three Is model can ensure that the least restrictive option is taken and that individual service users' independence is maximised by involving them in their care and treatment.

The model can empower service users through improved communication and information sharing, and by giving service users involvement in, and influence over, their care and treatment.

If service users are kept informed and involved, they will be treated with greater dignity and respect; if they are influential in decision-making processes, service users are more likely to feel empowered. Thus by ensuring service users are informed, involved and influential, a more equitable approach to decision-making processes can be taken.

It is important to note that implementation of the principles presented under each of the three Is in this article is as fluid as the prominence of each of the three Is at any given time during the shared decision-making process.

## Conclusion

In this article the authors discuss the relationship between decision-making forums in mental health inpatient settings are informed by mental health legislation and the professionals' roles as 'enforcers' of decisions. Where decisions are free from the constraints of mental health legislation, there is scope for higher levels of service-user involvement and influence.

It is therefore important for professionals to acknowledge such constraints by implementing the three Is model and do all that they can to increase the level of shared decision making when the constraints allow it.

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### Conflict of interest

None declared

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