Professional perspectives on service user and carer involvement in mental health care planning: A qualitative study

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ABSTRACT

Background: Involving users/carers in mental health care-planning is central to international policy initiatives yet users frequently report feeling excluded from the care planning process. Rigorous explorations of mental health professionals' experiences of care planning are lacking, limiting our understanding of this important translational gap.

Objectives: To explore professional perceptions of delivering collaborative mental health care-planning and involving service users and carers in their care.

Design: Qualitative interviews and focus groups with data combined and subjected to framework analysis.

Setting: UK secondary care mental health services.

Participants: 51 multi-disciplinary professionals involved in care planning and recruited via study advertisements.

Results: Emergent themes identified care-planning as a meaningful platform for user/carer involvement but revealed philosophical tensions between user involvement and professional accountability. Professionals emphasised their individual, relational skills as a core facilitator of involvement, highlighting some important deficiencies in conventional staff training programmes.

Conclusions: Although internationally accepted on philosophical grounds, user-involved care-planning is poorly defined and lacks effective implementation support. Its full realisation demands greater recognition of both the historical and contemporary contexts in which statutory mental healthcare occurs.

What is already known about the topic?

- Involving service users and carers in mental health care planning is central to international health policy and practice. Despite these long standing initiatives, the majority of users and carers still feel marginalised during the care planning process.

- Service users are motivated to collaborate in care planning but substantial barriers are created through poor information exchange and insufficient opportunities for participatory decision making.

- The perspectives of the professionals who are tasked with providing the majority of care to mental health service users have traditionally been under-represented.

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What the paper adds

- Care planning is a meaningful platform with which to involve service users and carers in mental health care but this involvement is poorly defined and lacks effective implementation support.
- Full realisation demands greater recognition of the historical and contemporary contexts in which statutory mental healthcare occurs.
- Professionals identify on-going training requirements particularly in relation to user centred communication and relational skills.

1. Introduction

Involving service users and carers in mental health care planning and promoting shared decision making are central tenets of contemporary mental health policy (Commonwealth of Australia, 2009; Department of Health, 1999, 2000, 2008; HM Government, 2011; World Health Organisation, 2012). Over the last thirty years, outmoded concepts of paternalism, in which clinicians' beliefs and attitudes have been allowed to dominate treatment decisions, have progressively been eroded, first by a growing consumer movement and latterly by morally and philosophically accepted concepts of therapeutic partnerships, relational equipoise and service user expertise. A dominant choice agenda is now a central cross-cutting principle of the World Health Organisation's Mental Health Action Plan (2012).

Consumerism infused the health policy of many countries in the 1980s as part of a market ideology that promoted individual patient choice and acknowledged the importance of healthcare satisfaction (Tait and Lester, 2005). In the United Kingdom, such concepts were gradually developed and expanded to include an acknowledgement of patients as experts in their own illness and thus an element of reciprocal responsibility in care planning and treatment decisions (Hickey and Kipping, 2002). Today, user and carer involvement is an established policy mandate, most recently consolidated by a new personalisation agenda for adult social care across England and Wales (Department of Health, 2008; Healthcare Commission, 2008b; HM Government, 2011; Secretary of State for Health, 2012). Similar developments have occurred overseas, with international research and policy imperatives upholding the importance of participatory mental healthcare and its perceived role in improving the culture and responsiveness of services and the quality of care that users receive (Commonwealth of Australia, 2009; Daremo and Haglund, 2008; Goodwin and Happell, 2008).

The central and unfailing premise of modern health policy is that users and carers are major stakeholders in service delivery and, as such, must be regarded as participants rather than simply recipients of mental health care. Small scale studies suggest that involving service users and carers in the planning and delivery of care can have positive effects on service and individual outcomes (Simpson and House, 2002; Thornicroft and Tansella, 2005); reducing rates of enforced admission and treatment for people with severe mental illness (Henderson et al.,

2004), increasing user esteem, and empowering individuals to regain control over their own recovery and care (Henderson et al., 2009). Yet, despite the philosophical and empirical support for user involvement, substantial evidence suggests that its translation into practice has not been easy to achieve.

At the beginning of the new millennium, Peck et al. (2002) proposed a framework for user involvement in mental health services, with user participation operating at four main levels. These levels pertained to (i) interactions between service users (self-help), (ii) interactions between users and health professionals (individualised care planning), (iii) local service management opportunities and (iv) service planning. Although the application of this framework in a UK setting identified a growing diversity of involvement initiatives, the majority of activities remained at a tokenistic level, with service users framed predominantly as subjects of consultation rather than agents in control (Tait and Lester, 2005). The strength and consistency of the views garnered at the time led some commentators to assert that there existed 'conflicting evidence as to the existence of [involvement] philosophies in the reality of mental health nursing practice' (Anthony and Crawford, 2000).

A recent systematic review of the international literature, specifically focused on user involvement in mental health care planning, reveals comparable findings (Bee et al., in press). Although substantial evidence suggests that users are sufficiently motivated to collaborate in care-planning, substantial barriers continue to be created through poor information exchange and insufficient opportunities for participatory decision making. National and international research literature is consistent in indicating that the majority of users and carers feel marginalised during the care planning process (Jakobsen and Severinsson, 2006; Mental Health Council of Australia and Carers Association of Australia, 2000), and that this lack of involvement occurs in both inpatient and community settings (Care Quality Commission, 2009; Healthcare Commission, 2008a). At best therefore, policy imperatives remain inconsistently implemented, and at worst are challenged or diluted by more ritualised practice.

Implementation theory suggests a number of possible explanations for the sustained translational gap. These include individual or communal appraisals of the concept and worth of user involvement, the quality of the relationships that exist between stakeholders, the organisational environments in which these relationships occur, and the autonomy and capacity of the implicated agents in facilitating change. Early small scale studies emphasised the potentially prohibitive roles of organisational influences (Anthony and Crawford, 2000); finite resources (Bowl, 1996) and professional resistance to user involvement (Crawford et al., 2003), with observed differences between mental health professionals' outward support for collaborative engagement and service users' perceptions of their frontline behaviour (Campbell, 2001).

Less clear are the reasons why such discrepancies exist and to what extent they continue to impact on contemporary mental healthcare practice. Potential reasons include