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Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare

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ABSTRACT

Migrants and ethnic minorities are under-represented in spaces created to give citizens voice in healthcare governance. Excluding minority groups from the health participatory sphere may weaken the transformative potential of public participation, (re)producing health inequities. Yet few studies have focused on what enables involvement of marginalised groups in participatory spaces. This paper addresses this issue, using the Participation Chain Model (PCM) as a conceptual framework, and drawing on a case study of user participation in a Dutch mental health advocacy project involving Cape Verdean migrants. Data collection entailed observation, documentary evidence and interviews with Cape Verdeans affected by psychosocial problems (n = 20) and institutional stakeholders (n = 30). We offer practice, policy and theoretical contributions. Practically, we highlight the importance of a proactive approach providing minorities and other marginalised groups with opportunities and incentives that attract, retain and enable them to build and release capacity through involvement. In policy terms, we suggest that both health authorities and civil society organisations have a role in creating 'hybrid' spaces that promote the substantive inclusion of marginalised groups in healthcare decision-making. Theoretically, we highlight shortcomings of PCM and its conceptualisation of users' resources, suggesting adaptations to improve its conceptual and practical utility.

1. Introduction

Public participation in healthcare decision-making is increasingly regarded as fostering more responsive policies, better services and, consequently, healthier populations (Frankish et al., 2002; WHO, 2006). Perhaps because of these promises, it is sometimes assumed that accomplishing inclusive participation is just a question of "getting the mechanisms and methodologies right" (Cornwall, 2008: 279). In practice, however, user participation is challenged by various constraints (Simmons and Birchall, 2005; Renedo and Marston, 2014), affecting some groups more than others. Migrants and ethnic minorities are particularly under-represented in the spaces created to give citizens voice (Sozomenou et al., 2000). Lack of awareness of opportunities for participation, insufficient mobilisation efforts, lack of resources and mismatches between users' aims and the aims favoured within participatory spaces undermine their involvement (Ibid.; Rutter et al., 2004; De Freitas, 2013). Excluding minority groups from the health participatory sphere may neglect alternative understandings that challenge dominant constructions of health and healthcare (Campbell et al., 2010), weakening participation's capacity to promote transformative change (De Freitas et al., 2014)—that is, participation that is "underpinned by a dialogical orientation" (Aveling and Jovchelovitch, 2014: 36) and which thus has the potential to transform preconceived understandings and result in wider change, rather than reinforcing prior positions and power relationships (cf. Campbell et al., 2010; Aveling and Martin, 2013). Moreover, it may produce or exacerbate health inequities, as policies and services become increasingly adapted to the demands of

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vocal majorities (WHO, 2006; El Enany et al., 2013). This is especially problematic when healthcare systems are dominated by market principles, where preferences of patients are constructed in consumerist, individualised terms, and social-structural constraints on healthcare provision are disregarded (Campbell, 2014). The need to broaden the demographic representativeness of participatory initiatives to include marginalised groups, such as poorer and minority-ethnic groups, has been identified in many OECD healthcare systems (e.g. Martin, 2008a).

So far, few empirical studies have focused on what works to bring marginalised groups into health participatory spaces. This paper seeks to help fill this gap by examining the factors that influence minority service users' decisions to get involved and stay engaged, through study of a successful mental health advocacy project hosted by a Dutch user organisation. We use Simmons and Birchall's (2005) Participation Chain Model as our conceptual starting point. This model attempts to offer a comprehensive understanding of the conditions required to enable and sustain involvement, including (i) 'demand-side' factors (the incentives that encourage users to become involved), (ii) 'supply-side' factors (the resources users need to participate, and efforts to mobilise them), and (iii) the 'institutional dynamics' of involvement itself (the way participatory processes, positively or negatively affecting continued involvement). While the Model seems to offer a clear inventory of the necessary and sufficient conditions for involvement, we highlight shortcomings in its conceptualisation, and suggest modifications with important theoretical and practical consequences for the model's use in informing participatory initiatives that value the contribution of marginal groups.

2. Background

Political encouragement for citizen engagement in healthcare has increased considerably in recent decades, "levering open arenas once closed off to citizen voice or public scrutiny" (Cornwall, 2004: 75). These developments are part of a wider shift toward participatory governance originating from concerns with unresponsive services and rising democratic deficits, and demands from increasingly diverse constituencies for inclusion in decisions affecting their lives (Barnes et al., 2004a).

The creation of participatory spaces to which ordinary people are invited has emerged as a key strategy for promoting participatory governance and enhancing democracy (Ibid.). These *invited spaces* (Cornwall, 2004) are expected to reduce the gap between state and citizens by operating as an interface for dialogue and collaboration in, for example, ensuring fairer distribution of the social determinants of health. However, invited spaces have been criticised in many studies, which highlight how, far from being transformative, they leave existing power relationships unaddressed, resulting in the imposition of established norms of conduct and unexamined preconceptions about service provision (Barnes et al., 2004a; Rose et al., 2010; Campbell et al., 2010). For marginal groups who demur from such hegemonic assumptions, such as migrant and ethnic minority (MEM) groups and mental health service users, the result can be continued marginalisation, with invited spaces acting as spaces for the reassertion of dominant views and the delegitimisation of challenge founded in alternative forms of knowledge (Beresford, 2002; Barnes et al., 2004b), or the 'professionalisation' of portions of the marginal group whose input aligns with dominant views (El Enany et al., 2013). But invited spaces of this kind are not the only form of participatory space. In several countries, grassroots action has given rise to what Cornwall (2004) calls *popular spaces*. These may be more autonomous and subversive in nature, with potential to equip participants with the skills and confidence necessary to occupy and reshape spaces created 'from above' (Campbell et al., 2010; Aveling and Martin, 2013; Aveling and Jovchelovitch, 2014).

Popular spaces in particular hold tremendous potential to transform prior viewpoints, develop new knowledge, and foster development of provision which is more needs-oriented and accountable to users (Campbell et al., 2010; Vaughan, 2014). Invited spaces, too, despite their roots, can become forums of inclusivity and empowerment, where marginalised views are given greater attention (Cornish, 2006; Renedo and Marston, 2014; Renedo et al., 2015). Nevertheless, within both kinds of space, inequalities in socio-economic status, communication skills and self-confidence may lead some—usually those already marginalised—to silence themselves. These inequalities may also be instrumentalised by more powerful others to bar the entry or impede the influence of disadvantaged citizens in participatory spaces (Aveling and Martin, 2013; Aveling and Jovchelovitch, 2014). Thus unless specific efforts are made to guarantee participatory spaces' *inclusiveness* for all social groups, participation may actually reinforce inequalities instead of reducing them (Guijt and Shah, 1998). This demands attention to the issues of (i) how to recruit users from marginalised groups, (ii) the resources they need to participate and can offer through participation (e.g. alternative understandings that may be neglected by dominant approaches to healthcare provision), and (iii) how the dynamics of the participatory space itself (whether 'invited', 'popular' or a hybrid) value or suppress these alternative viewpoints. This paper addresses all three sets of issues, answering the central question: how can the contribution of marginalised groups best be encouraged, valued and sustained through participatory initiatives? In so doing, we start from the framework offered by Simmons and Birchall's (2005) Participation Chain Model, which as we explain next helpfully enumerates these issues.

3. Theoretical framework

The Participation Chain Model (PCM) (Fig. 1) seeks to provide "a systematic framework for understanding what makes public service users participate" (Ibid.: 260), covering the full range of conditions necessary for participation, including:

- individual and collective benefits that might derive from participation, and which thus motivate people to participate (*demand-side factors*);
- participants' prior resources, and the mobilisation process that encourages them to participate (*supply-side factors*);
- the *institutional dynamics* of participation, i.e. the way the participation process itself, as governed in part by wider institutionalised expectations and priorities, encourages or discourages participation.

Each on its own is a necessary but insufficient condition for

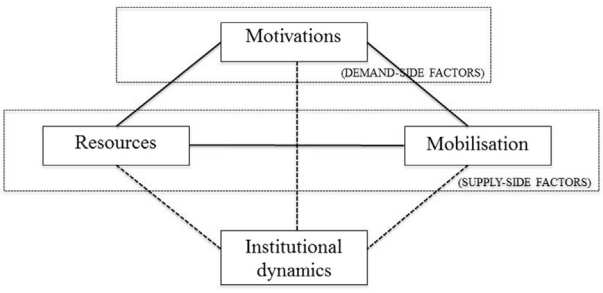

Fig. 1. Participation chain model. Source: Adapted from Figure 9 in Simmons and Birchall (2005: 278).