Historicising involvement: the visibility of user groups in the modernisation of the Chilean Mental Health System.

ABSTRACT

In western mental health systems, the involvement of user organisations has become an important dimension of contemporary policy development. But the processes constituting users as a relevant/irrelevant group have received little investigation, especially outside the English-speaking world. Drawing on Luhmann’s theory of society, this article presents a reconstruction of involvement initiatives in mental health policy in Chile between 1990 and 2005. It is based on 17 oral history interviews with policy-makers, high-level professionals, involved users, ex-users, and family activists, drawing also on relevant policy documents. Five processes are identified. In the early 1990s, the relevance of family groups as care providers in the context of deinstitutionalisation shaped the first encounters between psychiatry and community. Later, user groups became relevant as political supporters of the Mental Health Department’s funding requests, and in their capacity to legitimise decisions on involuntary treatment. The first National User Organisation resulted, in 2001. Its relevance was quickly undermined, however, by the AUGE health reform which restricted the definition of diseases and treatments with reference to evidence and costs. The legitimation of users was no longer needed and efforts to involve them subsided. Thus, we argue that the way in which the mental health system observes the voices of users is less a result of the actual status of users’ organisations than of the changing needs of mental health policy for ‘user representation’. By highlighting the contingency of policy shifts, we suggest that this historical and systemic perspective provides grounds for the strategic irritation and transformation of mental health systems through users’ activism.