Chapter 11

# Building healthcare stakeholder coalitions: a community psychology approach to user involvement for migrant populations

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#### 1. Introduction

In the context of what many regard as the most severe economic crisis ever suffered by the European Union (EU), efforts to improve healthcare should be given more priority than ever, because health problems can be expected to increase. Not only due to the stress associated with times of economic scarcity, but also because of increasing health and healthcare inequities. In particular, immigrants and low-income populations experiencing unemployment and substandard living conditions are more vulnerable to disease and health problems (Blouin *et al.*, 2009). A key challenge faced by the EU is the need to reduce healthcare inequities for the most vulnerable groups, including immigrants and ethnic minorities. All populations deserve the provision of adequate, accessible and quality healthcare, independent of gender, ethnicity, migration status, country of origin and socioeconomic status (EC, 2009).

The active involvement of users, articulating their voices, concerns, and perceived needs, must play a key role in this. This can be achieved through empowering strategies, in particular by applying the community-based participatory research methods of Community Psychology, which stresses doing research 'with' people rather than 'on' them. It promotes the active involvement of all the relevant stakeholders through diverse forms of collaborative alliances with researchers, policy makers, healthcare professionals, community organizations and healthcare

users (García-Ramírez et al., 2003; García-Ramírez et al., 2009; Suarez-Balcazar et al., 2005).

The main purpose of this chapter is to propose an approach to user involvement for migrant populations using community psychology principles (Nelson & Prilleltensky, 2005). A framework that emphasizes the key role of stakeholder coalitions for empowering communities will be presented (Balcazar *et al.*, 2012; Maton, 2008; Paloma *et al.*, 2010). In Section 2 we will highlight the key role of user involvement in assuring effective and equitable healthcare for migrant populations. In Section 3, user involvement for migrant populations will be examined from the perspective of community psychology (Balcazar *et al.*, 2012; García-Ramírez *et al.*, 2011; Hernández-Plaza *et al.*, 2010; Prilleltensky, 2003, 2008, 2011; Suarez-Balcazar *et al.*, in press). Healthcare stakeholder coalitions (HSCs) will then be described and examined in Section 4 as *empowering community settings*. This approach is then illustrated by the coalitions sponsored by the Virgen Macarena Hospital (VMH) in Seville (Spain). Finally, implications for future health initiatives are discussed.

### 2. User involvement and equitable healthcare for migrant population

Some of the most serious sources of inequity in healthcare for vulnerable groups like migrant populations are those related to socioeconomic factors, social exclusion, and the lack of sensitivity to diversity often demonstrated by healthcare professionals, practices and services (WHO, 2010). European public health experts agree that age, gender, migrant status, ethnicity, education and maternal language are among the individual characteristics of prospective patients that make them more likely to suffer marginalization and discrimination (SEKN, 2008).

This is illustrated by the demographic profile of female healthcare users in Andalusia, which has changed as a result of a significant increase in the number of immigrant women. It is primarily a young, working population, in the fertile phase of life, whose healthcare demands are closely associated with reproduction (conception, pregnancy, birth and childcare), and for whom maternity represents the main reason for hospitalization (Salazar *et al.*, 2003). In Andalusia, births by immigrant women account for around 30% of the total (Oliver *et al.* 2007). Higher maternal, newborn and child morbidity and mortality among immigrant women are to some extent due to inequities and deficiencies in treatment during pregnancy, at child-birth and in the postnatal period (Machado *et al.*, 2009). Acculturative stress, the adverse socioeconomic situation of immigrant women, which is often characterized by precariousness and marginality, and the lack of sensitivity to cultural diversity shown by health practitioners and their policies are some of the factors involved in the vicious circle of disadvantage experienced by many immigrant women and their offspring (Oliver *et al.*, 2007).

This was the challenge faced by nurses and midwives of the VMH maternity service when they decided to revise their practices related to the promotion of breastfeeding and to develop a protocol sensitive to the cultural diversity of women who become mothers. The multiple and heterogeneous socio-demographic profiles of women healthcare users (e.g. of Latin American, Moroccan, Sub-Saharan or Chinese origin) presented a challenge to this maternity service. Healthcare users may show a wide range of practices deriving from traditional health beliefs and folk practices, in particular relating to newborn diet, that sometimes do not reflect the health recommendations made by national and international health organizations. Initiatives oriented to promoting breastfeeding may also play a synergic role in the reduction of inequities, as they must begin before childbirth and have a positive impact on newborn health; nevertheless, for them to be adopted by migrant mothers, these initiatives need to be applied in a culturally sensitive and appropriate way (Oliver et al., 2007).

These types of healthcare initiative often fail because of a gap between theory and practice. The aim of disseminating and implementing 'good practices' is often thwarted by unjustified underlying assumptions of socioeconomic and cultural homogeneity (Padilla *et al*, in press; Trickett, 2011; Wandersman, 2003). One frequently suggested recommendation to overcome these barriers is to promote the active involvement of users. Users should participate in decision-making regarding how target groups wish to be defined, how they define their health needs, strategies to address them, the kind of services they need and how they define successful outcomes (Garcia-Ramirez & Hatzidimitriadou, 2009).

At present, however, the voices of the disadvantaged are not heard, still less taken into account, when designing policies or interventions. The result is that, despite the best of intentions, these are often rejected by the people they are designed to help. Community-based research proposes building alliances between researchers and disadvantaged groups in order to ensure that research projects, interventions, practices and services actually benefit those whom they are designed to assist.

There have been many calls for the building of community interventions that reflect the complex and multi-causal nature of migrant health inequalities (Frohlich & Potvin, 2008; McLeroy et al., 1988). Green (2001) has proposed that global and multicultural societies need to discard the simplistic assumption that the objective of healthcare research is to find, disseminate and implement 'magic bullet' interventions applicable to all communities. As a more realistic alternative, he has suggested that the focus of research should shift to community-based good practices which match needs, resources and contexts. More recently, Trickett et al. (2011:1410) have argued that these recommendations "reflect research-based and community-based concerns about the ecological validity of community interventions (i.e., the extent to which research conditions approximate in vivo conditions) and the critical role of local knowledge, hopes and involvement in the community intervention process". User

involvement is recognized as the key to research and interventions intended to ensure that healthcare systems are equitable as well as effective.

Community-based practices have been identified as "processes based on critical insights regarding the relationship between intervention scientists, professionals who implement interventions, the communities with which they work, and the structural and symbolic dynamics of power and privilege that operate within and upon these communities" (Sandler, 2007:279). Such practices can become socio-political development processes, enriching and empowering users and other stakeholders. Research is needed to clarify how participants acquire critical awareness about health needs, health promotion, and healthcare inequalities; how researchers and practitioners engage with particular communities; how professionals acquire cultural competence and sensitivity to user diversity; and how community members can get involved in practical terms (Suarez-Balcazar et al., in press).

The promotion of user involvement through community-based participatory processes requires that healthcare organizations have adequate human and technical resources to promote, support, and empower the involvement of all stakeholders, while giving a central role to actual and potential users. As we shall see in Section 5, the VMH included in its organizational structure the so-called 'Research Room, aimed at developing 'culturally relevant practice-based evidence' from initiatives, suggestions and ideas made by users, clinicians and other groups involved in healthcare (e.g. administrative staff, health workers, family members, informal caregivers). The 'Research Room' is a group rather than a place, and comprises a community psychologist, two nurses and a number of student nurses, each assigned to one of several initiatives. These students work as technical and research assistants (e.g. doing literature searches, data analysis, surveys). The group has strong links with community leaders and patient associations. At the same time, it requests collaboration from academic researchers who are experts in the specific matters of their projects. Participation of users is promoted through collaborative work in coalitions where all the relevant stakeholders are involved. The 'Research Room' acts as a bridge, a catalyst and instigator of coalitions, a conflict mediator and an advocate.

## 3. Community psychology and user involvement

Community psychologists emphasize the study of individuals in their natural environments, interacting in their own settings (Rappaport, 1977; Trickett *et al.*, 1985; Rappaport & Seidman, 2000). Community psychology has embraced an appreciation of human diversity and self determination as part of its definition, principles, and theoretical approaches. This approach suggests a conceptualization of user involvement characterized by respect for human diversity and culture; an emphasis on the empowerment of individuals, groups and communities; the promotion of

organizational and social change; the values of equity and social justice; and an ecological and psycho-political approach through community-based participatory research (Suarez-Balcazar *et al.*, in press).

Specifically, by adopting the community psychology approach, we can respond to the challenges associated with taking equitable measures for the active involvement of migrants in their own healthcare, supported by the following principles (García-Ramírez *et al.*, 2011; Kral *et al.*, 2011; Mankowski *et al.*, 2011; Paloma *et al.*, 2010; Tricket, 2011; Ward & Kagitcibasi, 2010):

- User involvement enables the roles of culture and context to be jointly redefined, observing the relationship between the psychological processes, linking individuals and their local communities, and healthcare organizations and systems, as integral elements inherent in the notion of culture. As a result, there is an interest in analyzing the dynamics of cultural exchange that redirect the identities, attitudes and behaviours of individuals in culturally changing healthcare settings.
- User involvement means adopting an interdisciplinary orientation to collaboration and methodological pluralism, in order to take advantage of the opportunities that the perspective of healthcare issues offers to researchers, service providers, and members of different cultures.
- User involvement promotes and enhances an ecological orientation emphasizing the influence of the particular settings and contexts in which individuals live their lives and interact on a daily basis, as they perform their roles and occupations.

In accordance with these principles, community psychology encourages researchers to promote community-based participatory research with immigrant populations, in order to provide them with voice and opportunities for action to identify, articulate and address their health concerns (Jason *et al.*, 2004). A community-based participatory approach emphasises the capacity of communities to sustain practices they helped to design and find useful for their wellbeing (Trickett, 2011). Healthcare stakeholder coalitions (HSCs) which emphasize the central importance of the most vulnerable members of communities, have been used as an effective tool to design, develop, implement and evaluate healthcare initiatives.

Fawcett *et al.* (1997) defined a coalition as a group of persons and/or organizations sharing common interests and agreeing to work together in order to achieve common goals. A coalition is formed out of groups with different interests, putting together their material and human resources in order to pursue common goals and specific tasks that the coalition's members could not achieve individually (Foster-Fisherman *et al.*, 2001). This means that coalitions have to be aimed at a specific problem, must develop their own structure, and must be focused on specific goals external to the coalition itself. They should have members with

different capacities, abilities, knowledge and resources (Butterfoss, 2007). Forming a coalition is a way for its partners to get involved in new and broader issues without the burden falling on only one organization or individual. Coalitions promote innovations that meet the needs of their constituents, maximize the power of individuals and groups, minimize the duplication of efforts and services, help mobilize resources for implementing actions, and promote the recruitment of participants from different backgrounds (Feighery & Rogers 1989; Roberts-De Genmaro, 1986).

HSCs encourage the development of collaborative capacities associated with building a sense of community and a culture of learning. This endeavour has also been referred to as creating *communities of practice* among stakeholders, in which individual members gain understanding, voice, and influence over decisions that, in turn, influence their actions (Berkowitz & Wolff, 2000; Fetterman *et al.*, 1996; Florin *et al.*, 2000; García-Ramírez *et al.*, 2009). Foster-Fishman and colleagues (2001) identified four core competences and processes needed to construct collaborative capacity among partners in community coalitions:

- 1. building individual members' capacity by helping them develop skills and knowledge about working in collaboration, and by encouraging positive attitudes and motivation for collaboration;
- 2. building relational capacity by promoting positive internal relationships among members, as well as external relationships with other coalitions;
- 3. *building organizational capacity* by fostering effective leadership, teamwork, communication, and procedures, as well as sufficient resources; and
- building programming capacity by moving in logical steps towards a series
  of successive realistic goals, driven by community needs, with culturallycompetent designs of action programmes.

# 4. Healthcare stakeholder coalitions as empowering community settings

As illustrated in Figure 1, HSCs may be understood as empowering community settings in terms of the following dimensions:

- Capacity to share a multicultural vision, embracing equity and diversity as
  values; recognizing diversity of origin, cultural and linguistic experiences;
  adopting models of services and care centered on the patient; acknowledging the special needs of immigrants and vulnerable populations; and including reciprocity, compromise and collaboration as guiding principles;
- 2. Adaptation of organizational processes (policies, standards and procedures) to the needs of culturally diverse users; obtaining and sharing proven evidence and good practices that integrate knowledge and the views of multicultural users of services; developing evidence-based practices, as well as gathering practice-based evidence and strengthening responsive delivery;

- 3. Promotion of horizontal and reciprocal relationships by including all stakeholders and partners in the decision making process; establishing strong partnerships with other researchers and organizations; and fostering the exchange of ideas and multicultural approaches among multicultural communities, community groups and professionals;
- Creation of capacity to engage in new roles, such as cultural mediators, community gatekeepers, and volunteers; training individuals as service providers, including spiritual and cultural healers;
- 5. Promotion of leadership among professionals, researchers and community members who are pluralistic, multicultural individuals, capable of representing equally firmly the needs and views of all constituents, and able to relate comfortably with multicultural communities;
- 6. Securing quality and systems change, instead of pursuing a 'quick fix' approach to addressing changes in services, with a focus on long-term social change, seeking to maintain the quality of services and to encourage changes in practices and policies (e.g. migration policies, health policies, employment policies, housing policies) that support culturally diverse populations and endorse equity.

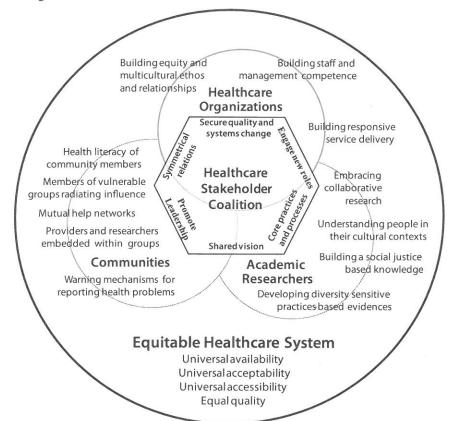
Conceptualization of HSCs as empowering community settings has enabled the promotion of healthy communities, advancement towards a more equitable organization for healthcare, and the generation of relevant academic knowledge based on the needs of the community (Garcia-Ramirez *et al.*, 2009; Maton & Brodsky, 2011; Paloma *et al.*, 2010; Suarez-Balcazar, *et al.*, 2004). As an example, the initiative devised and implemented by the 'Research Room' of the VMH aimed at promoting breastfeeding in migrant communities (Habas *et al.*, 2007) is summarized here.

# 5. Case study: the HSC formed to promote breastfeeding among VMH communities

For the promotion of breastfeeding, the 'Research Room' of the Hospital Virgen Macarena in Seville established alliances with CESPYD (the Coalition for the Study of Health, Power and Diversity¹), based at the University of Seville (Spain), and composed primarily of community researchers and immigrant organizations, collaborating with colleagues from the University of Illinois at Chicago (UIC) and the University Institute of Lisbon (CIES-IUL) in the development of community-based research.

The underlying framework was supported by a re-definition of equity in healthcare based on the 'Standards of Practice for Culturally Competent Health-

Figure 1. Healthcare Stakeholder Coalitions as Empowering Community Settings



care' proposed by the Transcultural Nursing Society (Douglas et al., 2009) and the Amsterdam Declaration of the MFH network. According to these standards, user involvement within coalitions helps users to be critically aware of their values and beliefs, more effective communicators (communication being understood as a symmetrical relationship), and to acquire political competence for the implementation and evaluation of culturally-relevant competent healthcare (see Wandersman, 2003 and Wandersman et al., 1999, 2000).

To build up this HSC, natural alliances and people already working in breast-feeding were identified in order to invite them to join the coalition. Four nurses from the maternity service involved in breastfeeding programmes, two specialized care midwives, and two primary care midwives were invited to be members of the coalition. Four physicians, two paediatricians, and two gynaecologists were also invited to participate. Importantly, two activist immigrant women, representative of the largest immigrant groups in the area served by the VMH (Moroccan and

<sup>1</sup> www.cespyd.org

Latin American), also participated in the process. Other members of the coalition were a representative of an association involved in the promotion of breastfeeding; the directors of the Obstetrics and Gynaecology units; a nurse from the 'Research Room'; and a psychologist from the CESPYD. The maternity nurse supervisor led the coalition.

Although all members of the coalition shared a common concern with the need to promote breastfeeding among immigrant women, very soon it was clear that each group had their own particular goals. Nurses and midwives looked for working procedures and ways of action defined and agreed with physicians and other healthcare professionals. Immigrant women wanted to incorporate their cultural practices into medical protocols and increase their opportunities to make decisions in conditions equal to those enjoyed by autochthonous women. Primary care professionals wanted to reach consensus on coordinated actions before, during and after childbirth, with specialized health professionals at the hospital.

The best strategy for achieving a wider collective goal is to guarantee that the narrower particular objectives of each of the groups involved will also be attained. In order to merge the interests and needs of all the groups involved, short-term goals were defined, focusing on the need to develop abilities for collaborative work. Theoretical and practical workshops were held, focusing on collaborative work in coalitions and the promotion of sensitivity to the cultural diversity of users among health professionals. A system of communication and information within the coalition was developed, based on a list of information distribution by e-mail, a telephone list, a free access blog, and a three-monthly informative bulletin. All members of the coalition were familiarized with the use of internet and electronic mail, and were trained in communication skills in scientific and community contexts.

For the longer term, the following goals were established: a) to integrate scientific evidence, the experience of professionals, the perceived needs identified by associations of both immigrant and autochthonous users, and the resources available for implementation of actions; b) to prepare the contexts where changes in professional practices were to be promoted, with the aim of facilitating their acceptance by all the professionals involved; and c) to establish appropriate evaluation systems. Concerning the review of existing scientific evidence, a brief working document was given to the coalition, focused on the most relevant good practices in the promotion of breastfeeding. Users' cultural practices and living conditions were critically examined for relevance and possible incorporation in future protocols. In this way, the protocol for action was constructed on a collaborative basis.

The directors of the Gynaecology and Paediatric Services acted as facilitators in the preparation of the context for change. Furthermore, culturally-sensitive informative posters were prepared, focusing on breastfeeding and the work being undertaken by the coalition, and were displayed in different locations of the hospital, primary care centres, and the organizations involved in the coalition. Considerable effort was put into disseminating information verbally among health professionals.

Informative leaflets on breastfeeding were also distributed, adapted to diverse cultural traditions, and translated into several languages (e.g. English, Chinese, Arabic).

Subsequently, the coalition drafted and reached consensus on a plan oriented to achieving the implementation of proposed changes in healthcare practices – the protocol. A pilot execution of this protocol was conducted over one month, followed by an evaluation of the coalition's work. This process allowed the coalition to examine critically the defined objectives, the efficacy of planned activities in the achievement of previously-defined objectives, and the possible need to make adjustments or changes in proposed actions. Collaborative work was disseminated in scientific and community meetings, incorporating feedback obtained and lessons learned.

#### 6. Implications and conclusion

In this chapter we have proposed an approach to user involvement in healthcare initiatives based on the principles, values and conceptual tools of community psychology. HSCs are suggested as a useful strategy for the accumulation of relevant and reliable knowledge through community-based collaborative alliances that can facilitate changes at different social, ecological and policy-making decision levels.

To summarize the potential benefits for *healthcare organizations*, HSCs are an excellent scenario for the promotion of community cultural competence in health professionals and others working this field. By collaboratively involving users, service providers and researchers, the HSC approach can enable us to understand cultural competence as a process, as a way of conceiving encounters between healthcare actors from different cultural backgrounds, in which practices and standards are designed, implemented, evaluated and sustained in a comprehensive, collaborative and empowering process (Suarez-Balcazar *et al.*, in press).

HSCs are understood as participatory and collaborative alliances that overcome the limitations of merely assuming that culturally-competent professionals will ensure culturally relevant interactions with immigrant users (Uttal, 2006; Weaver, 2005). One can assume that the adaptation of educational curricula ought to make practices and programmes more accessible and culturally appropriate (Weaver, 2005); or that the elimination of barriers to access ought to increase the utilization of services and the participation of users (Gross *et al.*, 2001). However, experiences like those described here demonstrate that active and direct user involvement is essential, right from the very initial phases of service planning, taking into consideration how immigrant users perceive their own needs and define their own problems.

HSCs should also help in resolving problems regarding *limited access to sensitive information about users* (e.g. ethnicity, legal status, sexual orientation). This

information is relevant because some of these factors determine immigrants' opportunities to access and utilize health services, to obtain social support, to get stable employment, appropriate housing or even adequate public transport, considering that health determinants are related not only to cultural factors but primarily to educational level, income, acculturation, working and living conditions, and legal status, among other factors (Hernandez-Plaza *et al.*, 2010; Luque-Ribelles, 2011; Paloma, 2011). In line with these propositions, HSCs incorporate the voices of users, not only as potential patients, but also as citizens participating in the construction of a fairer society.

HSCs are a mechanism with the proven *capacity of mobilizing communities*, making alliances with community leaders, integrating users as active agents, promoting social participation and generating positive relations between immigrant populations and other community groups, allowing them to gain capacities to respond to their own diverse health challenges, advocating and supporting immigrants in their collective actions aimed at gaining equal health rights, and so encouraging social justice (Balcazar *et al.*, 2004; García-Ramirez *et al.*, 2011). Users involved in HSCs may also become active agents of change in their own organizations and communities, as models and advocates of culturally-sensitive practices (García-Ramírez *et al.*, 2009).

Furthermore, HSCs foster and enable *health literacy* among community members, which is understood as another psycho-political empowering process (Albar *et al.*, 2010; Prilleltensky & Fox, 2007; Prilleltensky, 2011). Literacy in healthcare means power to attain wellbeing, equal access, acceptance and enjoyment of multicultural healthcare services and mutual responsibility (García-Ramírez *et al.*, 2011; García-Ramírez, 2012). This process is also associated with the acquisition of new links with organizations and mutual help networks, which develop and define new social references, increase the resources of migrant populations and, at the same time, increase their capacity to change unhealthy conditions. Finally, this process leads to their involvement in collective actions and activities in order to build healthy communities, incorporating members of immigrant groups who gain opportunities to influence both their communities and the healthcare system.

As a contribution to the *advancement of academic knowledge*, the involvement of user in HSCs allows them to have an impact on all levels of diversity and complex cultural dynamics, including differences in healthcare discipline cultures. Cultural and power dynamics associated with different disciplinary and professional cultures play a key role in the development of practices and standards (García-Ramirez *et al.*, 2009). Reich and Reich (2006) emphasize the promotion of health practices in contexts characterized by collaborative interdisciplinary work. Coalitions enhance awareness of members' own disciplinary culture and sensitivity towards others, and facilitate more creative solutions to community problems.

Potential benefits of collaborative alliances involving users are associated with enabling interdisciplinary cooperation, which in turn will reduce the fragmenta-

tion and duplication of efforts that result from artificial barriers between disciplines. Bringing different theoretical and methodological traditions in contact with each other, together with communities and users, stimulates a necessary degree of humility and tolerance among providers and researchers, and creates a body of knowledge and good practices, substantial enough to effectively influence national or international policies.

Another HSC project currently being developed in Lisbon (Portugal) sets out to promote equity and sensitivity to diversity in primary healthcare, incorporating the voices and promoting the active involvement of healthcare users with particular emphasis on disadvantaged populations, such as immigrant and native users living under conditions of poverty and social exclusion. This initiative has been supported by a Marie Curie Action Grant within the EU 7th Framework Programme (Heranández-Plaza, 2011). Also based on HSC and located in Lisbon, a parallel community-based participatory project focuses on the specific case of maternal health, through an interdisciplinary dialogue that incorporates the perspectives of community psychology, sociology and anthropology, emphasizing the voices and experiences of disadvantaged women (Padilla, 2011). Both projects will provide further support for collaborative work using HSCs in the European context. Whereas this approach has an extensive tradition and track record in the United States and Latin America (Balcazar et al., 2012; Cortes, 2009; Martín Baró, 1996; Maton, 2008; Nelson & Prilleltensky, 2005), it is only recently that efforts have been made to apply it in Europe.

We would state, in conclusion, that user involvement through HSCs promotes respect for human diversity as a worthwhile value in itself; it acknowledges that collaborative goals must be based on community needs, and that success depends on achieving real benefits for individuals and their communities. Therefore, it is a crucially important approach in the endeavour to build equitable healthcare systems, which must be a key goal for the EU, even though it is currently in serious economic and political difficulties. This chapter is a call to action to healthcare stakeholders in Europe, who should have the imagination and ability to work together with the objective of assuring adequate healthcare and welfare for their many and diverse social groups, thus strengthening Europe's role as a leader in achieving a fairer global future.

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PART 3

**OTHER ISSUES**