

4-30-2013

## What did we learn about citizen involvement in the health policy process: lessons from Brazil

Vera Schattan Pereira Coelho

*Brazilian Centre of Analysis and Planning, veraspc@uol.com.br*

Follow this and additional works at: <http://www.publicdeliberation.net/jpd>



Part of the [Public Affairs, Public Policy and Public Administration Commons](#)

---

### Recommended Citation

Coelho, Vera Schattan Pereira (2013) "What did we learn about citizen involvement in the health policy process: lessons from Brazil," *Journal of Public Deliberation*: Vol. 9 : Iss. 1 , Article 9.

Available at: <http://www.publicdeliberation.net/jpd/vol9/iss1/art9>

This Symposium is brought to you for free and open access by Public Deliberation. It has been accepted for inclusion in Journal of Public Deliberation by an authorized editor of Public Deliberation.

---

# What did we learn about citizen involvement in the health policy process: lessons from Brazil

## Abstract

In this paper I argue that citizen involvement helped to promote a more equitable distribution of public health services in Brazil. This achievement involved a balance of contributions from social actors and health system managers in forging policy innovations and institutional arrangements that linked bottom up innovation with national policy leveraging and decentralized implementation. The paper briefly describes this cycle and its relation with the implementation of a national network of forums for citizen involvement in health policy, inquiring in more detail the conditions that favor the association between these forums and the policy making process. Our results do not corroborate the idea that deliberative arenas should be insulated from political passions; rather, they suggest that participation of mobilized social actors contributes to the effectiveness of these forums. This contribution happens both due to the knowledge that these actors bring about problems in the area and to their insertion in networks that connect forums to a wide set of social organizations and political, governmental, and health institutions, which in turn facilitate the dissemination and negotiation of the proposals and demands formulated by the forums. However, our results also suggest that the inclusion of these actors increases confrontation to the detriment of deliberation, which brings us to the discussion of the role that could be played by mediators who are well-equipped to construct deliberative processes.

## Keywords

health councils, participation, deliberation, mobilization, Brazilian Public health System (SUS), participatory democracy, deepening democracy, civil society

## Acknowledgements

A version of this paper was presented to a group of practitioners and scholars who participated in a symposium on public deliberation in health policy and bioethics at the University of Michigan in September 2010. This two-day symposium, organized by Julia Abelson, Susan Goold, and Erika Blacksher, asked the twenty-five researchers in attendance to reflect on questions about rationales, methods, uses, and impact of public deliberation in the health sector. This article presents results from the 'Participation and Health Policy in the City of São Paulo' research programme carried out by CEM-INCT/CEBRAP/NCD with support from FAPESP and CNPq; and The Citizenship Development Research Centre (CDRC/IDS – Sussex University) with support from DFID. The case was developed as part of a comparative research program on Citizenship, Participation and Accountability in the South (CDRC). I would like to thank John Gaventa, Suzan Goold, Mark Warren and Shylashri Shankar for their comments to previous versions. Senior researcher at the Center of Metropolitan Studies and at the Brazilian Center of Analysis and Planning where she coordinates the Citizenship and Development Group.

In the beginning of the 1980s it became clear in Brazil, as well as in a number of other countries, that greater resources for public healthcare were allocated to wealthier regions and citizens. Over the next few years, the difficulties in overcoming this distributive pattern gained momentum in the public policy literature and by the end of this decade there were different pathways being described as possible avenues to overcoming distributive inequalities in the health sector. Of the several possibilities being discussed at this time, two gained the particular attention of governments, scholars and donors: citizen involvement and decentralization. The idea was that both could contribute by promoting innovation, accountability for the needs of the poorest citizens, and social control.

In Brazil this agenda gained political relevance after the enactment of the “Citizen Constitution” in 1988. In addition to declaring health to be a universal right of citizens, the Constitution replaced the old public health system with the SUS, or Unified Health System. At the time of its creation, the SUS reflected the aspiration for a system that integrated the local, the state and the national levels as well as preventive and curative medicine. Recent data show that the SUS has, in its 20 years, been working for the poor, as efforts have successfully been made to achieve a more balanced distribution of resources between the worse and better off regions. Also, in addition to the reduction of inter- and intra-regional inequalities, there has also been a decline in health inequalities between the population as a whole and some of Brazil’s most vulnerable groups (MS, 2010).<sup>1</sup> Nevertheless, there was also a small increase in the inequality in the distribution of basic services within the poorest areas and groups, which I will refer to as horizontal inequalities<sup>2</sup> (Shankland 2010, Coelho et al 2010a).

The paper analyses the role played by citizen involvement throughout this policy process and discusses features that can be improved in order to strengthen the processes’ accountability to the most vulnerable and least mobilized groups. To do so, in the next section I begin by briefly reviewing the debate on citizen involvement and policy change. In section three, I describe the cycle of innovation that emerged during the 1990s within the SUS and which made positive distributive outcomes possible while highlighting the role played by citizen involvement in this process. In section four, I focus on the formal arenas for citizen involvement, established along the aforementioned cycle. I then propose a model that should allow for more systematic comparisons between these formal arenas. This model was tested with a small selection of cases. Despite the small number of cases analyzed, they suggest a positive association between mobilization and a decrease in inequalities in the distribution of health services, while also showing a negative association between mobilization and deliberation. Finally, in section five, a discussion is presented based on these results, which concerns features that may contribute to the establishment of a more positive relationship between mobilization, participation and deliberation. This positive relationship could represent an opportunity to tackle horizontal inequalities.

---

<sup>1</sup> See Annex 1, which presents data on Brazil showing a reduction in inter-regional inequalities and data for the Municipality of São Paulo showing a reduction in intra-regional inequalities.

<sup>2</sup> Horizontal inequalities refer to inequalities that grow between groups that depart from similar socio-economic features. They result from a process where sub-groups leave behind other sub-groups with whom they had shared membership of a broader, formerly excluded group (“peasants,” “indigenous people,” “the urban poor,” etc.).

## *2. Linking citizens to the policy decision making process: a brief overview of the debate*

Theorists of deliberative democracy, deepen democracy, and participatory governance have been discussing how procedural, institutional, and social features can improve the quality of citizen involvement in policy issues. Authors associated with deliberative democracy theory believe that the core idea of democratic deliberations is that decisions are made with more and better information and these decisions come to be accepted as legitimate and justified by participants. They call attention to the process of decision-making and offer nuanced criteria for assessing the quality of these processes (Habermas 1997; Dryzek 2001; Mansbridge 2003). Those associated with deepen democracy argue that citizenship should mean far more than just the enjoyment of legal rights and the election of representatives, highlighting citizens' potential to collectively mobilize in order to be directly involved in deliberation and decision-making on political and policy issues (Gaventa and Cornwall 2001; Heller 2001; Avritzer 2002). Finally, those associated with participatory governance are particularly interested in how to coordinate these new and participatory political arenas with the congressional and executive governmental bodies. They inquire about the institutional framework in which these bodies interact with a view to developing and implementing policies that are more accountable to citizens' needs (Fung and Wright 2003; Melo and Baiochhi 2006).

Departing from these perspectives, there have been a number of studies in recent years on Southern and Northern empirical experiments that are concerned with deliberation and participation. Authors working with 'new democratic arenas' in the South suggested that under certain conditions concerning design, the mobilization of civil society and involvement by public managers, redistributive gains and an increase in the political participation of traditionally marginalized groups in the political process do occur (Abers 2001; Wampler and Avritzer 2004; Coelho and Nobre 2004; Lavallo et al. 2005). Researchers focused on deliberative experiments that took place in the North in turn have demonstrated that deliberative processes contribute towards changing the positions and opinions of participants, attenuating the process of polarization concerning controversial policy issues (Abelson and Gauvin 2006).

More recent studies point out that, despite this good news, important questions with respect to the democratic potential of these new democratic arenas remain unanswered (Melo and Baiocchi 2006; Cornwall and Coelho 2007; Dagnino and Tatagiba 2007; Bebbington, Abramovay and Chiriboga 2008; Warren and Urbinatti 2008). For example, in Brazil, India or South Africa, given the rules that organize participation in participatory processes, how can we check whether traditionally marginalized groups with no political party connections or relationship with public managers were included in the process or accessed its distributive benefits? Furthermore, how can we tell if there is greater accountability in the way that the policies are being provided? Are the public policies that are being generated from information provided by civil society representatives innovative?

These empirical findings on citizen involvement confirm the relevance of the theoretical approaches described earlier – deliberation, mobilization and governance – and, at the same time, call attention to the fact that these perspectives have been studied separately. They also highlight that there is currently no well established knowledge about the quality of the processes or their capacity to impact the policy process.

To begin to deal more systematically with this kind of question, we developed a methodology that helps to assess how far public involvement in health policymaking has come in promoting inclusion, connections with relevant actors, proactive participation and a more equitable distribution of public health resources. We also inquired about the relationships between, in one hand, these features and, in the other hand, social mobilization as well as forum design.

To investigate the extent to which public involvement promotes inclusion, participation and connections, we followed the approach of a group of researchers (House and Howe 2000; Rowe and Frewer 2004; Abelson and Gauvin 2006, Ansell and Gash, 2007) who have highlighted the need to construct models that make it possible to analyze and compare arenas for citizen engagement. At the core, for these authors, is the possibility of identifying procedures and incentives that favor the expression of demands by those who have fewer resources. The focus here is that the rules of the game can orientate the behavior of the agents and have a decisive impact on the capacity of the participatory forums to translate into procedures and norms the desired objectives of a given policy, as well as altering the balance of power between the participants, favouring the expression of demands by those who have less resources. From this perspective, because different forms of organizing participatory processes can lead to different policy outcomes or diverse deliberative dynamics, it is, therefore, important to produce knowledge which enables us to measure the relationship between procedural variables in the most systematic way (Fung 2004, 2005). These authors also recognize the importance of investigating the location of these arenas within governance structures.

To deal with the impact of different types and trajectories of mobilization in the forums' performance, we followed another group of authors (whose ideas are published in Cornwall and Coelho (eds. 2007) who suggest the importance of social mobilization processes in guaranteeing conditions so that actors that have fewer resources are able to participate. As we pointed out before, much of the 'Deepening Democracy debate' addresses the idea that the success of participatory or decentralisation experiences is somehow dependent on the associative contexts where they are implemented. On one side of this debate several authors have been arguing that decentralisation processes or the creation of participatory institutions are not sufficient incentives to stimulate social mobilisation. These authors highlight the importance of the processes of identity formation and their role in the mechanisms of collective action as a way of dealing with these limits, avoiding the 'empty' spaces and guaranteeing efficient conditions for the participation of actors that have less resources (Gaventa 2004, 2005; von Liers and Kahane, 2007; Cornwall 2007; Mohanty; Mahmud). In a parallel route, authors who deal with the wide notion of *social capital* contend that desirable levels of participation, deliberation and positive political outcomes can only possible be obtained in social environments with some record of civic engagement and political mobilisation (Putnam 1993; Verba et al., 1995; Costa 1997).

Inquiring about these features and at the same time following the distribution of public resources invested in health facilities in a given area helps to describe the forums and produce data that can be used to test hypotheses related to the role of design, as well as of social and state actors in defining the performance of the forums.

In this paper I present a preliminary set of findings that resulted from the application of this model, with the expectation that they will contribute to a better understanding of the conditions and mechanism that link participation to the policy decision making process. In the next section, before entering into this analysis, I briefly present the innovations that guaranteed the institutionalization of a robust framework for citizen involvement in Brazil. In doing so, I hope to make the nature of the mobilization processes to which I am referring clearer, as well as the type of health governance structure currently in effect today in Brazil.

### *3. Bringing the citizenry back in: describing a cycle of innovation*

The innovations that made it possible for the SUS, the Brazilian Public Health System, to successfully tackle entrenched inequalities over the last twenty years are related to the story of the Health Movement. In the mid-1970s, the poor peripheries of large cities grew and there was a sharp increase in demand for basic services. Over the course of these mobilizations, a battle for health services emerged and in the 1980s the Health Movement was consolidated around the struggle for a universal health movement waged by its militants, many of whom were workers in the public health system and had the opportunity of holding public office at the municipal, state and federal levels.

The “Brazilian Health Movement” played a crucial role in disseminating the notion of health as a citizen’s right and advocating for the institutionalization of citizen’s participation in the formulation, management and monitoring of health policy. Its trajectory has much in common with other popular movements born during the period of Brazil’s redemocratization. It was organized around priests in the Catholic Church, neighborhood associations, leftist activists and public health workers. Furthermore, there was a coming together of intellectuals, students and artists, all of whom played an important role in forging a pact between progressive bureaucrats and citizens, which helped to ensure a bottom-up process, with decentralized (civil society and municipal or state level) programs being created in the late 1980s and successfully tested before becoming National Programs in the 1990s as, for example, the local health councils, the Health Family Programs and the HIV-AIDS initiatives.

During this process, a new governance structure was forged and, in the 1990s, contracts begun to be established between the federal, state and municipal governments, which defined responsibilities and transparent financing rules for the implementation of the national health policy. At that time the effective institutionalization of the health conferences, a national health council, and the health councils in all twenty-six states and in nearly all of the 5,561 municipalities also took place.

The federal government, through the Ministry of Health, became responsible for setting the national guidelines for health care at all three levels of complexity (basic, intermediate, and high-complexity) and provides financial support to states and municipalities. The SUS is financed entirely by public resources at the three

levels of government (federal, state and municipal)<sup>3</sup>. In 2010, federal funding covered approximately 44% of public expenditures<sup>4</sup>, and half of this is transferred directly<sup>5</sup> to states and municipalities. States are in charge of coordinating the services provided within their territories, linking basic, intermediate and high-complexity services and supporting poor municipalities. Municipalities are responsible for the provision of basic care and the referral of patients to higher-complexity services; they handle users living in both rural and urban areas. In the policy implementation cycle, health councils and conferences play a decisive role in regularly engaging civil society in a way that allows for challenges to be posed to the Health Authorities on policy and, as a result, there is increased transparency and accountability. At the local level, municipal health councils contribute by monitoring services - such as the distribution of medicine - while also campaigning for the construction of new hospitals and health units in poor areas. This approach has helped to address inter-regional inequalities, since it promotes coordination between the three levels of government as well as responsiveness to the needs of the different regions.

This brief overview suggests that the distributive achievements described earlier were dependent on a policy process that helped the development of a porous boundary between state and society actors, which made it easier to advance a specific institutional arrangement that promoted regular debate between policymakers, health professionals and service user representatives. In the next section, we focus on the experience of the health councils that were implemented through this cycle, investigating the conditions under which they can effectively contribute to the inclusion of citizens in the policy process in a way that makes policy more accountable to their needs.

#### *4. Investigating features of citizen involvement and its distributive impacts*

Health councils (HCs) address core issues of priority-setting and accountability. They also approve annual plans and health budgets. If the plans and accounts are not approved, the city does not receive funding from the Health Ministry. It is important to note that although their legal powers reside mainly in the technical and administrative spheres, the councils are especially significant for their role in policy discussion (Mercadante 2000). Their substantive contribution is the expansion of public spaces with the possibility of open discussion and deliberation on health policy.

The authors who have analyzed these councils have reached ambivalent conclusions about their capacity impacts. While a number of cases presented

---

<sup>3</sup> In 2009, total expenditure for the health sector was equal to 9% of GDP (US\$144.2 billion); of this total 46% were public expenditures and 54% were private expenditures) (WB 2012).

<sup>4</sup> Ministério da Saúde, 2012.

<sup>5</sup> The decentralization of health care responsibilities, carried out in the late 1980s, created a specific form of direct resource transference between the Federal Health Fund and all the state and municipal health funds - called *Transferência Fundo a Fundo* (TFF - Fund to Fund Transfer). Since the reforms kept the Federal Government as the main tax collector, but reassigned most of the service-delivering obligation to the states and municipalities, the TFF ensures the sub-national administration an automatic and regular fund transfer, without the need of legal contracts that would otherwise be necessary.

relatively little achievement, there were also a number of successful cases. In these analyses, success was sometimes recognized as the capacity to include marginalized citizens, and at other times, as the ability to work as schools of citizenship or as the capacity to present innovative proposals. At still other times, success was recognized as the capacity to promote distributive gains in favor of the poor. As previously noted, these successes were interpreted as being the result of good design, or of the organization of civil society, or of the involvement by committed public managers. Nevertheless, these conclusions came through a collection of case studies, while there were not, in fact, methodological instruments to move towards a systematic comparison of these experiences. To fill this gap, we began to work on a model of analysis that would allow for evaluation and analytical integration of both the drivers of change and distributive impacts mentioned above.

The first step was to develop a model that differentiates between inclusion, participation and connections in the HCs. We also typified the debates and decisions that took place in the HCs. In doing so, we worked out indicators that characterize features related to two big questions in the field: who participates and how.

Concerning inclusion, from amongst the many possible criteria, we considered as ‘more inclusive’ those indicators that reflected participants associational and political plurality, a demographic profile that mirrors that of the population, and a socio-educational profile with significant presence of the poor and less educated. In short, we considered socio-economic, demographic, political and associative characteristics<sup>6</sup>.

Concerning participation, we looked for the features that can countervail power asymmetries between participants, as facilitation and organization of the agenda, and promote accountability of the participants to their constituencies, as well as the councillors’ own satisfaction with the process.

Concerning connections, we assumed as ‘more connected’ those forums that presented a high level of references - in interviews with councillors and minutes of meetings - to links with the executive and legislative branches at the municipal, state, and national levels. We also refer to the connections with other participatory forums, with other institutions in the health system and with other public and private organizations. We tracked formal and informal connections as our aim was to have a sense of the universe of persons and institutions recognized by the councillor’s ‘radar’.

In order to investigate the impact of social mobilization on these three dimensions, we selected cases (in areas with similar Human Development Indices) that had a significant history of social mobilization regarding health demands, and compared them with the results obtained for councils located in areas where there had been fewer of these mobilizations<sup>7</sup>.

We then classified the debates held as: health issues, including discussions about health policies and programs and problems with service delivery; participation issues, dealing with procedures for elections and meetings; and local problems, such

---

<sup>6</sup> Tables describing these variables are presented in Annex II.

<sup>7</sup> This classification was based on secondary research and was checked in interviews with specialists on social movements in São Paulo.



as water supply, infrastructure or security. Finally, we followed the distribution of public new health facilities in the municipality between 2001 and 2008.

To understand how the decisions made by the HCs entered into the policy decision making process we interviewed public officials. Below, I briefly describe the research and the findings.

Research took place in São Paulo, which has a population of more than 11 million and which is conspicuous for its sharp social inequality and unequal access to public services. Moreover, in 2000, after the leftist Worker's Party (PT) won municipal elections, the city was divided into 31 sub-municipalities, with a Technical Health Supervisor and a Local Health Council<sup>8</sup> established in each one (CEM 2002). It was under these conditions that we considered São Paulo to be an excellent 'laboratory' for our research.<sup>9</sup>

Map 1 presents the city with its 31 sub-municipalities and shows the Municipal Human Development Index (MHDI) figure calculated for each of them. As shown by the data, central districts had better human development indicators. It also presents the six sub-municipalities selected for our study, which are highlighted by green boundaries.

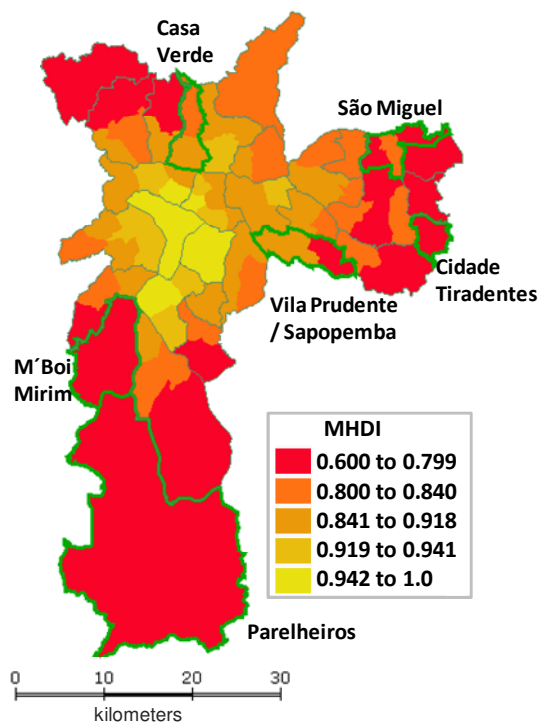
The 6 LHCs selected are located in poor regions of the city. Three of these - São Miguel, Cidade Tiradentes, and M'Boi Mirim - had a strong history of social mobilization regarding health demands, while in the other three - Casa Verde, Vila Prudente/Sapopemba, and Parelheiros - there had been fewer of these mobilizations.

The local health council (LHC) consists of 24 effective and 24 substitute councillors. The councillors that represent civil society self-identified as representatives of: popular health movements; health units; religious associations; neighborhood associations; Unions; civil rights groups; participatory forums; homelessness movements; landless peasants movements; community or philanthropic groups; disabled persons associations; or as non-affiliated representatives (Coelho, 2006).

---

<sup>8</sup> Local Health Councils were created in a number of Brazilian metropolises to support local administration as well as Municipal Health Secretariats and councils. They have similar functions to those of the Municipal Health Council but have no veto power, since they lack a constitutional mandate.

<sup>9</sup> The case study discussed in this paper (Coelho, Ferraz, Fanti and Ribeiro, 2010) builds upon previous research conducted on the creation and organization of São Paulo's thirty-one LHCs, carried out between 2001 and 2005 (Coelho, 2006), as well as on research concerning the distribution of health services in the Municipality of São Paulo, carried out between 2001 and 2008 (Coelho, Dias and Fanti 2010a).

**Map 1 – São Paulo's Sub-municipalities by Municipal Human Development**

Source: Atlas do Trabalho e Desenvolvimento (SMT).

The tables and graphs presenting the indicators calculated for the three dimensions under study – inclusion, participation and connections – as well as the analysis of the debates held are presented in Annex II<sup>10</sup>. The presence of a background of social mobilization proved itself to be an important factor in promoting more vibrant LHCs as well as in increasing the participation of the most vulnerable as shown by the greater inclusion of councillors with less education and women and non-whites on the councils located in the *sub-prefeituras* which had stronger backgrounds of mobilization. Also, the way debates are carried out is very different in areas with a greater or lesser history of mobilization. The results pointed out that in the sub-municipalities with a stronger history of mobilization, the LHC discussions were marked by more conflict and confrontation, but had better outcomes in the variables related to monitoring healthcare services and innovative proposals. As an example, in regards to the reduction of absenteeism, one suggestion made by the LHC that was implemented was to contact patients advising them of the date of the appointment. Also, monitoring of the construction of the two municipal hospitals built in the period helped in speeding the process. The organizations and the councils for these areas also present a greater number of connections with socio-political and institutional actors and have links to segments of bureaucracy, service providers, politicians and the civil society (Coelho et al. 2010).

<sup>10</sup> For a more nuanced picture see the disaggregate data

at: [http://www.centrodametropole.org.br/v1/dados/saude/Anexos\\_Artigo\\_Saude\\_CDRCCEM.pdf](http://www.centrodametropole.org.br/v1/dados/saude/Anexos_Artigo_Saude_CDRCCEM.pdf)

We also noted that in more mobilized areas this dynamic has contributed to promoting greater integration between the councils and their respective Technical Health Supervision Units (Coelho et al. 2010a). In a situation of heated disputes over resources between sub-municipalities, this integration with councils has been welcomed by supervisors of the Technical Units. After all, those with the support and endorsement of civil society will be in a better position to negotiate their demands with the Municipal Secretariat of Health. The gains from this strategy are reflected in the increased ability to raise funds as shown by the three sub-municipalities which have more active councils. For example, the only two municipal hospitals opened in the period were built in Cidade Tiradentes and M'Boi Mirim. It is true that these areas did not have any hospitals, but it is also true that six other sub-municipalities in the outskirts that presented low MDHIs were in the same situation and did not receive any public hospital in the period. Another example is given by the number of recently inaugurated Outpatient Health Units in these sub-municipalities. There were 16 units in the three sub-municipalities that have the most active councils vis-à-vis 10 in the 3 areas where the councils are less active. In this case, the second group should have had 15 units, if the distribution had only followed population distribution criteria. These results help to explain a distributive tendency reported earlier: a reduction in inequalities in the supply of services among areas that have the best and the worst socio-economic and health indicators, as well as a slight increase in inequalities in distribution of basic services within areas with the worst indicators (Coelho et al 2010a).

The results also have shown that in both areas, with greater and lesser mobilization, 'vivid' participation is limited, inasmuch as few councillors raised issues and sustained discussions about them. In this sense, the creation of these LHCs, which are testaments to an impressive institutional process of building participatory forums, was not accompanied by innovation in the day-to-day operation of these spaces. In many cases they contributed, in the more mobilized areas, to simply reproducing the positions of health movements. Curiously enough, in the group with weaker backgrounds of mobilization, aspects associated with procedures - design and election themes - appeared more frequently, suggesting that these LHCs are looking for changes in their dynamics

Despite the small number of cases analyzed, they suggest interesting relations between mobilization, LHCs and distributive impacts, drawing attention to the non-linearity of the gains described. The dimensions - inclusion, participation, and connections - and the indicators that we have chosen to represent them run in different directions, highlighting the complexities of citizen involvement in the policy process. In the councils located in the sub-municipalities with a stronger history of mobilization, we found greater socio-economic inclusion, but less political and associative plurality. Also, the discussions were less deliberative, marked by more conflict and confrontation and more resistance was offered to change in the procedures used to select representatives and organize the meetings. Yet, at the same time, better outcomes were presented in monitoring healthcare services and raising funds. On the other hand, the LHCs located in areas with less history of mobilization are the ones that worked out propositions to change procedures, which may favor new and more deliberative dynamics. They are searching for new ways to select the councillors and run meetings (Coelho et al. 2010).

On a final note, it is worth mentioning that in the last fifteen years growing resources have been expended in public health. However, the probability of continuing expansion is slight<sup>11</sup>. At the same time, other issues related to service quality, rising costs and an aging population are coming to the fore. In this scenario, it remains to be seen if the mechanisms described will endure or if new mechanisms, including more effective deliberation, will have to be considered. We turn to this discussion in the next section.

### *5. Reimagining citizen involvement in the SUS*

In this paper I have departed from the literature calling attention to the potential of citizen involvement in contributing to the democratization of the decision making process and its increased accountability to citizens. I have also reviewed a number of studies that researched empirical experiments concerning citizens' involvement in the policy process. While the empirical findings confirm the relevance of the existing theoretical approaches to explain successful cases, they also point out to the fact that there are several case studies dealing with a particular approach while there are few efforts to integrate these approaches as well as to develop systematic comparative studies.

In order to approximate these debates and allow for more systematic analyses, I have presented an innovative comparative research framework designed to make inquiries into the relations between social mobilization and designs features, in one hand, and, forum dynamics and distributive impacts in the other hand. Research has been focused on health councils that are part of a national framework for citizen involvement in health policy implemented during the mandate of political parties that supported the cause of greater citizen involvement. These councils were conceived as public spaces that could promote deliberation between civil society, public managers and service providers on health policy.

Because the methodology was tested with a small selection of cases in order to explore the plausibility of the hypothesis that relates social mobilization, participatory processes and distributive changes, it is worthwhile to proceed with caution, bearing in mind that the evidence presented above is more indicative than conclusive in nature. The results suggest that in a context of growing public health expenditures and governments that are supportive of the cause of participation, a positive association did occur between, on the one hand, mobilized social actors, their participation in health forums and the building of alliances with health managers, and on the other hand, a growing offer of health services to poor areas.

However, the picture that appeared through the study shows several nuances. In one hand, mobilization appeared related to inclusion, alliances with public officials and distributive gains. In this sense, mobilization brought dynamism to the forums and proved important in guaranteeing the inclusion of women, non-whites and non-

---

<sup>11</sup> In 1995, public expenditures reached US\$17 billion, going to US\$28 billion in 2006 (figures restated to reflect the worth of a dollar in 2000). In 2006, total expenditures were equal to 7.5% of the GDP (US\$ 58.5 billion), of which 48% were public expenditures and 51% were private expenditures. In 2009, total expenditure for the health sector was equal to 9% of GDP (US\$144.2 billion); of this total 46% were public expenditures and 54% were private expenditures) (WB 2012).

educated people in the health councils, as well as in promoting the councils' connection with state, social and market actors, which, despite the often confrontational style and the mechanical reproduction of the positions of the Health Movement, helped to disseminate the debates and struggles. The result was an increased ability to negotiate and bring health services to these areas. On the other hand, less mobilization seemed related to more openness to procedural innovation as themes such as design and election appeared more frequently, suggesting that these LHCs are looking for more deliberative dynamics and innovative proposals. In this sense, areas lacking a history of strong mobilization were open to procedural innovation that could lead to a more deliberative style of discourse and interaction.

The dynamics described earlier paint a rich picture of how top down and bottom up dynamics are interacting to shape the municipal health policy. These dynamics are probably similar to those that linked the health movement, health councils and health authorities throughout Brazil over the last twenty years, calling for greater attention to be paid to the crucial role that institutional rules together with the politics of public participation are playing in building the SUS.

The Brazilian experience with health councils offers important lessons concerning the possibilities of building a national network for citizen involvement in health policy. This experience suggests that insofar as the political parties and system managers acknowledge social actors as partners they gained an important ally in their struggle to overcome a biased and inequitable distributive profile. This disposition to acknowledge social actors as partners is not a trivial one; also, the very existence of organized social actors interested and capable of acting as partners cannot always be relied upon. Nevertheless, the case also calls attention to the risks of these mechanisms in reinforcing the exclusion of the less mobilized while promoting greater horizontal inequalities. This experience highlights an iterative process that nurtured the disposition of social, state and political actors to share responsibilities in the policy making process. As a final word, I would suggest that more attention should be given to the understanding of the conditions under which mobilized citizens and public officials may help in fostering the forums' accountability to non-mobilized citizens.

### Quoted Bibliography

- Abelson, J., Giacomini, M., Lehoux, P and Gauvin F. (2007). "Bringing 'the public' into health technology assessment and coverage policy decisions: from principles to practice". *Health policy*, vol. 82, pp. 37-50. Amsterdam.
- Abers, R. (2001). *Inventing local democracy: grassroots politics in Brazil*. Boulder CO: Westview Press.
- Ansell, C. and Gash, A. (2007 ). "Collaborative governance in theory and practice". *Journal of Public Administration Research and Theory Advance Access*. Vol. 18, nº 4, pp. 543-71.
- Avritzer, L. (2002). *Democracy and the Public Sphere in Latin America*. Princeton: Princeton University Press.

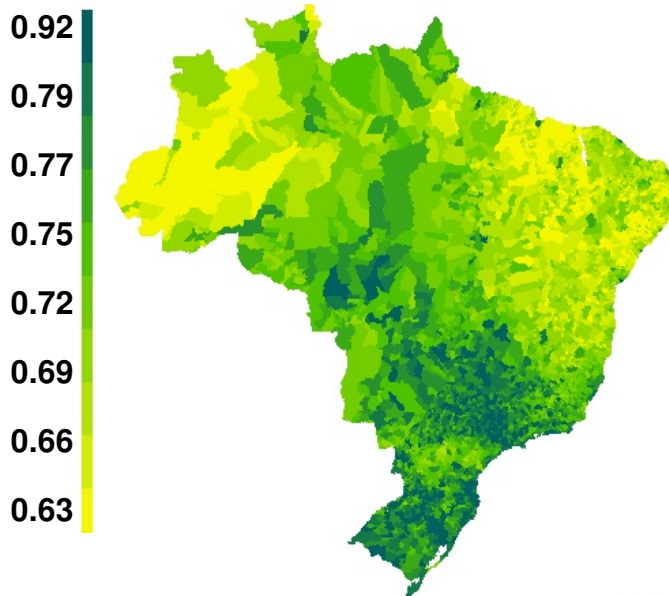
- Bebbington, A., Abramovay, R. and Chiriboga, M. (2008). "Social movements and the dynamics of rural territorial development in Latin America". *World Development*, vol. 36, nº 12, pp. 2.874-87.
- Coelho, V.S., Ferraz, A., Fanti, F. and Ribeiro, M. (2010). "Mobilização e participação: Um jogo de Soma Zero? Um estudo sobre as dinâmicas de conselhos de saúde da cidade de São Paulo". [Mobilization and Participation; A zero sum game?] *Novos Estudos*; nº 86, pag. 120 a 139. Editora Brasileira de Ciências. São Paulo.
- Coelho, V. S.; Dias, M. and Fanti, F (2010a). "Fighting inequalities in the access to health services: A study of the role of decentralization and participation" paper presented at the Metropolis and Inequalities International Seminar. CEM, São Paulo.
- Coelho, V.S. and Favareto, A. (2008). "Questioning the Relationship between Participation and Development: A case study of the Vale do Ribeira, Brazil," *World Development*, vol. 36, pp. 2937-2952.
- Coelho, V.S. (2006). "Democratization of Brazilian Health Councils: The Paradox of Bringing the Other Side into the Tent," *International Journal of Urban and Regional Research*, vol. 30, pp. 656-671.
- Coelho, V. S. and Nobre, M. (2004). *Participação e deliberação: Teoria democrática e experiências institucionais no Brasil contemporâneo [Participation and Deliberation in Contemporary Brazil]*. São Paulo: Ed. 34.
- Cornwall A. and Coelho V. (eds.) (2007). *Spaces for change? The politics of participation in new democratic arenas*. Londres: Zed Books.
- Costa, S. "Movimentos sociais, democratização e a construção de esferas públicas locais". *Revista Brasileira de Ciências Sociais*, 1997, vol. 12, nº 35.
- Dagnino, E. and Tatagiba, L. (2007). *Democracia, sociedade civil e participação*. Chapecó: Argos, 2007.
- Dryzek, J. S. (2001). "Legitimacy and economy in deliberative democracy". *Political Theory*, October, pp.651-669. London: Sage.
- Fung A. and Wright E. O. (2003). *Deepening democracy: institutional innovations in empowered participatory governance*. London: Verso, 2003.
- Gaventa J. and Cornwall A. (2001) "From users to choosers to makers and shapers: repositioning participation in social policy". *IDS Working Paper*. June, No. 127. Falmer: IDS.
- Habermas, J.(1984). *The Theory of Communicative Action*. London: Heinemann
- Heller, P. (2001). "Moving the State: the politics of democratic decentralization in Kerala, South Africa, and Porto Alegre". *Politics and Society*. Vol. 29; No.1; March; pp. 131-163.
- House, E. and Howe, K. (2000). "Deliberative democratic evaluation checklist". *Evaluation Checklist Project*.
- IPEA (2000). Instituto de Pesquisa Econômica Aplicada – IPEA Available at: <http://agencia.ipea.gov.br> > last Access 08/25/2010.

- Gurza Laval, A., A. Acharya and P. Houtzager (2005). 'Beyond Comparative Anecdotalism: How Civil and Political Organizations Shape Participation in São Paulo, Brazil', *World Development* 33(6): 951-961.
- Mansbridge, J. (2003) "Rethinking Representation". *American Political Science Review*. 97(4), November; pp: 515-28,
- Melo M, and Baiocchi G. (2006). "Deliberative Democracy and Local governance: Towards a New Agenda". *International Journal of Urban and Regional Development*. Vol. 30.3. September; pp:587-600. Blackwell Publishing. London
- Mercadante, O. "Conselhos Municipais de Saúde". Informativo CEPAM. Vol. 1; No. 3; Março; pp. 62-70. Fundação Prefeito Faria Lima. São Paulo. Brazil, 2000
- Monitoraids – Programa de acompanhamento de dados e pesquisas sobre Aidas no Brasil - Ministério da Saúde 2008. Available at: <http://sistemas.aids.gov.br/monitoraids/> > last access 08/25/2010
- MS - Ministry of Health –Data for Infant mortality rate, available at: [http://portal.saude.gov.br/portal/saude/profissional/visualizar\\_texto.cfm?idtxt=32203&janela=1](http://portal.saude.gov.br/portal/saude/profissional/visualizar_texto.cfm?idtxt=32203&janela=1) > last access 08/25/2010
- Putnam R. (1993). *Making Democracy Work*. Princeton University Press: New Jersey.
- Rowe, G. and Frewer, L. J. (2004) "Evaluating public-participation exercises". *Science, Technology & Human Values*, vol. 29, n° 4, pp. 512-56.
- Shankland A. (2010). 'We got in our heads that we should do the job of the State': The Indigenous Peoples' Movement, forest citizenship and struggles over health services in Acre, Brazil". In V. Coelho and B. von Lieres (eds). *Mobilising for Democracy: Citizen Engagement and the Politics of Public Participation*. London: Zed Books (forthcoming).
- SIOPS - Sistema de informações sobre orçamentos públicos em saúde –, Available at: <http://siops.datasus.gov.br/> > last access 08/25/2010
- SMS - Municipal Secretary of Health. Health indicators available at: <http://www.prefeitura.sp.gov.br/cidade/secretarias/saude/tabnet/> > last access 08/25/2010
- Wampler, B. e Avritzer, L. (2004 ). "Públicos participativos: Sociedade civil e novas instituições no Brasil democrático" In: V. Coelho e M. Nobre. *Participação e deliberação*. São Paulo: Ed. 34.
- WHO, 2010 Health Resources available at: <http://apps.who.int/ghodata/>> Último acesso em 25/08/2010
- Urbinati, N. and Warren, M. (2008). "The Concept of representation in Contemporary Democratic Theory". *The Annual Review of Political Science*. V. 11; pp: 387-412.
- Verba, S., Schlozman, L.K. and Brady, H. (1995). *Voice and equality: Civic voluntarism in American politics*. Cambridge: Harvard University Press.

## Annex 1

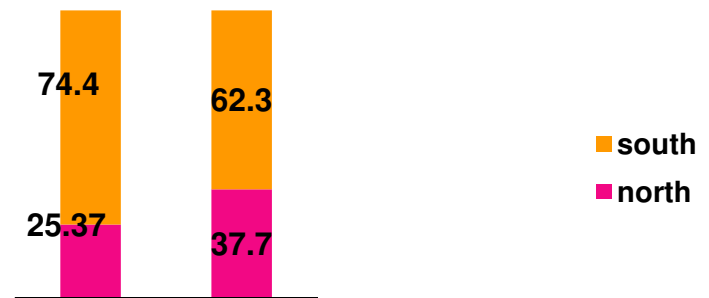
### Municipal HDI

2000, Brazil



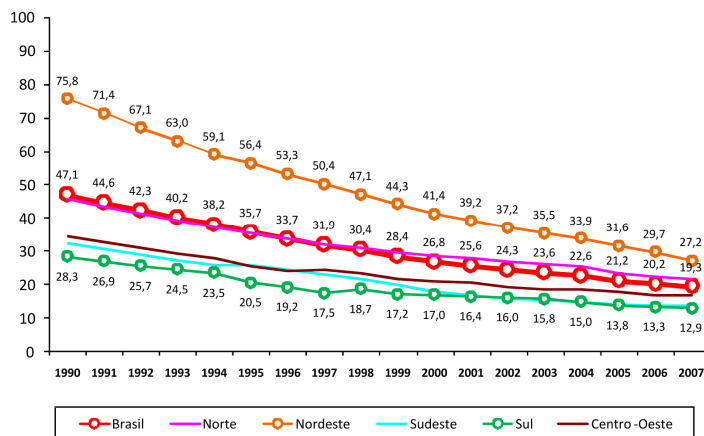
Source: IPEA, 2000

### Regional Distribution of resources for health assistance, Brazil, 1986-2006



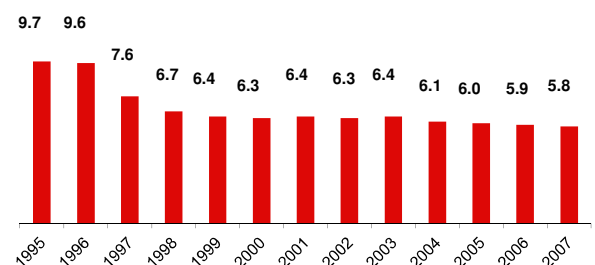
Source: SAS/MS (1986); Siops (2006)

### BRAZIL - Infant Mortality Rate (per 1000 live births), 1990-2007



Source: MS – Health Ministry, 2010

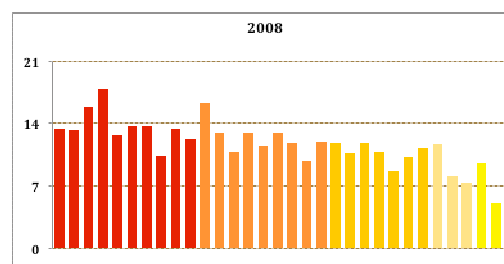
### Brazil - Aids Mortality Rate (Death per 100.000 habitants), 1995-2007



Source: Monitoraids, 2008



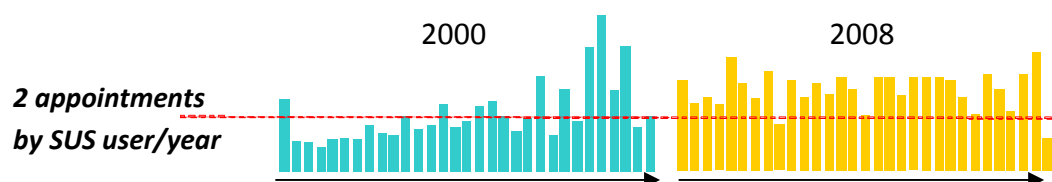
## Infant Mortality Rate, São Paulo, Sub-Municipalities, 2000 and 2008



São Paulo's sub-municipalities, ordered by crescent HDI

Source: Municipal Health Secretary. Chart: CEM/Cebrap

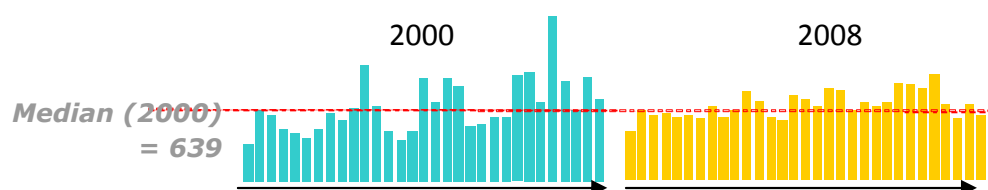
## Primary appointments per SUS user/year, São Paulo, Sub-municipalities, 2002 and 2008



São Paulo's sub-municipalities, ordered by crescent HDI

Source: Municipal Health Secretary. Chart: CEM/Cebrap

## Hospital Admission by 10.000 SUS user/year, São Paulo, Sub-municipalities, 2002 and 2008



São Paulo's sub-municipalities, ordered by crescent HDI

Source: Municipal Health Secretary. Chart: CEM/Cebrap

## Annex 2

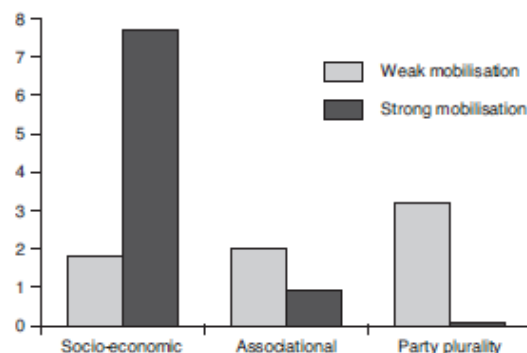
Tab. 1 – Types of inclusion in six LHCs located in areas with different histories of mobilization

Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parel- heiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Gender	similarity to distribution in the population.	1	0	0	0	1	1
Skin colour	similarity to distribution of whites and non-whites in the population.	0	0	0	1	0	1
Education	representation of councillors with low level of education.	0	0	0	1	0	1
Income	representation of councillors with low income.	0	1	0	1	0	1
Party plurality	presence of representatives across the political spectrum.	1	1	1	0	0	0
Associations	number of types of association represented.	1	0	1	0	1	0

Lighter grey: sub-prefeituras with a weaker history of mobilization.

Darker grey: sub-prefeituras with a stronger history of mobilization.

Note: 1. Councillors reported themselves as representatives of popular health movements, health units, religious associations, neighbourhood associations, unions, civil rights groups, participatory fora, homelessness movements, the landless peasants movement, community or philanthropic groups, disabled persons associations, or as non-affiliated representatives.

**Graf. 1 - Types of inclusion in six LHCs located in areas with different histories of mobilization**

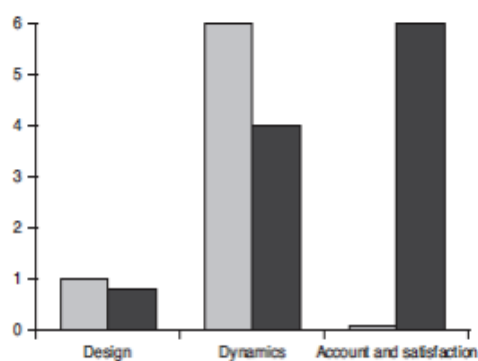
Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Tab. 2 - Features of Participation in six LHCs located in**

Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parelheiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Selection procedure	transparency in selection of councillors.	0	0	0	0	0	0
Facilitation	Presence of facilitator.	0	0	0	0	0	0
Agenda	% of meetings coordinated by non-manager councillors.	0	1	0	0	1	0
Themes	balance of themes on council agenda.	0	0	1	1	0	0
Right to speak	participation of non-manager councillors.	0	1	1	0	0	1
Right to speak	participation of non-councillors.	0	1	0	0	0	1
Environment	number of councillors contributing in council meeting.	0	1	0	0	1	0
Environment	number of times a single councillor contributed in a council meeting.	0	1	1	1	0	0
Accountability	number of media used by councillors to keep constituencies informed.	0	0	0	1	1	1
Satisfaction	councillor satisfaction about running of council	0	0	0	1	1	1

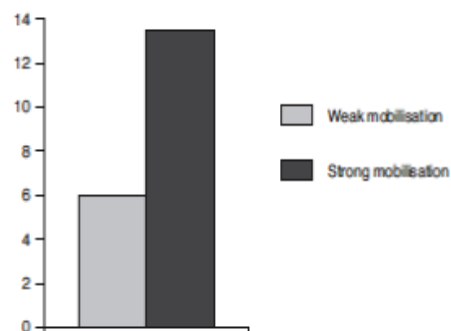
Lighter grey: sub-prefeituras with a weaker history of mobilization.  
Darker grey: sub-prefeituras with a stronger history of mobilization.

Note: 1. The value 1 was attributed to the councils where the agenda presents an equilibrium between issues concerning health policies; specific problems in the local health units; regional problems and procedures connected to the functioning of the forums.

**Graf. 2 - Features of Participation in six LHCs located in areas with different histories of mobilization**

Indicator	Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parelheiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Manager	mentioned by councillors in questionnaire.	0	0	1	0	1	0
Politician	mentioned by councillors in questionnaire.	0	0	0	0	1	1
State body	cited in council minutes.	0	1	0	1	0	0
Executive and Legislature	identified by councillors as having a relationship with the organizations they represent	1	0	0	0	1	1
Health Unit	cited in council minutes.	0	1	0	1	1	0
Organization	cited in council minutes.	0	0	1	0	1	1
Association	councillors representing an association.	0	0	1	0	1	1
Participatory Forum	cited in council minutes	0	0	0	1	1	0

Lighter grey: sub-prefeituras with a weaker history of mobilization.  
Darker grey: sub-prefeituras with a stronger history of mobilization.

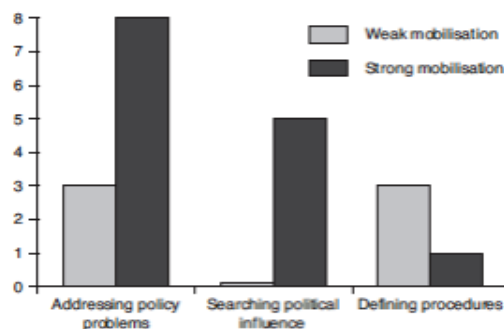
**Graf. 3 - Connections by six LHCs located in areas with different histories of mobilization**

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD

**Tab. 4 - Type of theme debated in six LHCs in areas with different histories of mobilization**

Criteria Score of one indicates greater ...	Vila Prudente	Casa Verde	Parelheiros	M'Boi Mirim	Cidade Tiradentes	San Miguel
Positioning about policy issues or making demands.	0	0	1	1	1	1
Planning, partnership or innovation.	0	0	1	1	1	1
Monitoring.	0	0	1	1	1	0
Recognizing cultural and ethnic diversity.	0	0	0	1	1	1
Expanding political influence.	0	0	0	1	1	0
Defining procedures for participation and electoral processes.	1	1	1	1	0	0

Lighter grey: sub-prefeituras with a weaker history of mobilization.  
Darker grey: sub-prefeituras with a stronger history of mobilization.

**Graf. 4 - Type of theme debated in six LHCs in areas with different histories of mobilization**

Source: Health Policy and Public Involvement in the city of São Paulo Project, 2008 – CDRC/CEM/NCD