

Disability Policies and Politics:  
A New Perspective for Brazilian Disability Citizenship?  
Lyusyena Kirakosyan  
Virginia Polytechnic Institute and State University

Author Note

Lyusyena Kirakosyan, ASPECT - Alliance for Social, Political, Ethical and Cultural Thought, Virginia Polytechnic Institute and State University.

Correspondence concerning this article should be addressed to Lyusyena Kirakosyan, 202 Major Williams Hall (0192), Virginia Tech, Blacksburg, VA 24061, United States

Contact: [lyusyena@vt.edu](mailto:lyusyena@vt.edu)

### Abstract

Public policies aimed at assisting disabled citizens are a fairly recent development in Brazil. Prior to the advent of the nation's relatively new rights-based policies, the politics of "assistencialism"—policies aimed at addressing the symptoms and not the causes of social ills—served as a rationale for such support as was provided to the nation's disabled population. Civil society organizations have been fundamental in Brazil to advance the rights of disabled people. This article argues that civil society organizations and the state must act vigorously and jointly if assistencialism ultimately is to be overcome and full citizenship for disabled Brazilians is to be attained.

The analysis is organized into three parts. First, it briefly describes the evolution of the struggle for rights for disabled Brazilians during the past three decades. Second, the article examines the government's recent rights-based policies and advocacy organizations' claims. The article concludes by offering a brief analysis of how the contemporary policy initiatives have contributed to the development of Brazilian citizenship and democracy.

*Keywords:* disability policy, democracy, civil society, citizenship, Brazil.

Les politiques et les pratiques en faveur des personnes handicapées :

Une nouvelle perspective pour les citoyens handicapés du Brésil?

### Résumé

Les politiques publiques ayant pour but de porter aide aux citoyens handicapés sont assez récentes au Brésil. Avant l'introduction des politiques basées sur les droits des personnes handicapées, qui sont relativement neuves, les politiques "assistencialistes"—des politiques ayant pour buts d'adresser les symptômes et non les causes des problèmes sociaux—servaient de justification pour les services qui étaient fournis aux personnes handicapées. Les organismes de la société civile ont été

fondamentaux au Brésil pour faire avancer les droits des personnes handicapées. Cet article maintient que les organismes de la société civile et l'État doivent travailler vigoureusement ensemble pour que l'assistencialisme soit finalement supplanter, et pour que les personnes handicapées Brésiliennes puissent enfin avoir accès à une citoyenneté à part entière.

L'analyse est organisée en trois parties. Premièrement, elle décrit brièvement l'évolution du combat pour les droits des personnes handicapées au Brésil au cours des trois dernières décennies.

Deuxièmement, l'article examine les politiques gouvernementales récentes qui sont basées sur les droits des personnes handicapées, ainsi que les demandes de représentations des organismes de défenses des droits des personnes handicapées. Finalement, l'article conclut en offrant une analyse qui explore comment les initiatives contemporaines de politiques pour les droits des personnes handicapées ont contribué au développement de la citoyenneté et de la démocratie Brésilienne.

*Mots Clefs:* Politiques du handicap, Démocratie, Société civile, Citoyenneté, Brésil

Disability Policies and Politics:  
a New Perspective for Brazilian Disability Citizenship?

Prior to ratification of Brazil's democratic Constitution in 1988 and its incorporation of new rights assurances, "assistencialism"<sup>1</sup> served as a rationale for support provided to the poor and to disabled people. Predicated on a "charity for the afflicted" mindset, assistencialism produced dependency among its recipients while doing little to address the root causes of inequality that disabled Brazilians confronted. Paulo Freire (1973) argued that this politics constituted violence against human freedom, robbing those already marginalized of conditions essential to developing their ability to "open" their consciousness and thereby of their opportunity to become full citizens (p.15).

The new Constitution guaranteed Brazilians equal civil, political and social rights and raised hopes for dramatic change for those oppressed by existing social inequalities. Although disabled Brazilians had gradually built an organized movement by the time the new Constitution was debated nationally, it was not until 2008 that the Brazilian state assumed formal responsibility for promoting and guaranteeing the civil, political and social rights of disabled people. This article employs a three-part analysis to explore ongoing efforts to attain rights for disabled Brazilians in light of these realities. First, it outlines the historical evolution of the struggle for equal rights for marginalized Brazilians in general and those with impairments in particular, over the past three decades. Second, the article examines the recent rights-based policy efforts of Brazilian government and claims and

---

<sup>1</sup> Freire (1973) used the term "assistencialism" to describe "policies of financial and social assistance which attack symptoms, but not causes, of social ills" (p.15). The assistencialist perspective entailed tutelage of disabled citizens, thus constraining their freedom to make decisions and assuming responsibility for those choices. "Assistencialism" created strong resistance among advocates of disability rights in Brazil as the movement became more organized (Lanna Júnior, 2010).

actions of disability advocacy Civil Society Organizations (CSOs). The purpose of the analysis is to evaluate the degree to which these efforts hold promise to help Brazil secure ‘double democratization,’ which David Held (1996) has pointed to as an appropriate social aspiration. The article concludes with a brief analysis of whether, and how, these initiatives have contributed to the development of a new frame for Brazilian citizenship and democracy.

This article draws on fieldwork carried out in Brazil in the summer of 2011 when I conducted individual semi-structured interviews with seven leaders of disability-related CSOs. My goal was to explore the justice-based claims advanced by each organization to promote disability rights. The interviews furthered my insights into the challenges the nation faces in conceiving and carrying out policies within the new United Nations (UN) approach that originated with adoption of the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD). Brazil’s disability-related CSOs have been among primary stakeholders in generating, maintaining, reproducing and transforming justice and disability discourses within the nation’s policy-making processes. In addition to the interviews conducted, I examined available governmental and nongovernmental reports and websites in order to explore the development of disability rights in Brazil in recent years.

Throughout this article, I refer to ‘disabled people’ to point to those with various impairments, who are oppressed and the targets of discrimination, or ‘disabled’ based on their society’s values and attitudes. These constitute socially oppressive structures that marginalize and render such people powerless. Shakespeare (2006) states that although there is no disability without impairment, the latter is a necessary, but not always a sufficient cause of the difficulties that disabled people experience (p.34). Disability does not wholly result from discriminatory social practices and

institutions, as adherents of the social model<sup>2</sup> argue. Instead, disability is the result of interaction between an individual and structural factors or, in other words, it is the consequence of the relationship between elements intrinsic to the individual (nature and severity of the impairment, their own attitudes to it, their abilities and personality) and contextual factors (enabling or disabling environment, wider cultural, social and economic values, attitudes and interests) (Shakespeare, 2006, pp.55-56). I use the terms ‘impairment’ and ‘disability’ advisedly, bearing in mind a conceptual link between both: impairment may or may not be tied to disability and social oppression, but there is no disability without impairment<sup>3</sup>.

### **The evolution of the struggle for rights in Brazil**

This section provides a brief overview of the struggle for equal rights in Brazil during the last three decades, with a particular focus on disability rights. It sketches the context of re-democratization in the late 1980s and then focuses on the struggle for citizenship rights for disabled Brazilians.

Democracy was formally restored in Brazil in 1985 when civilian government was re-established after 21 years of military dictatorship. However, the establishment of the new regime did

---

<sup>2</sup> The social model regards disability to be a result of the way society is organized. Because society is ordered unjustly, and in ways that privilege nondisabled persons and bodies, people with impairments face attitudinal, environmental and institutional discrimination.

<sup>3</sup> Impairment and disability have often been conceived in terms of the biological features of a person that deviate from society’s culturally established normality—physical, intellectual and emotional attributes. Pothier and Devlin (2006) also agree that depending on what is valued, or perhaps overvalued, in a society, specific personal characteristics may be understood as defects (p.5). The notion of impairments remains controversial and has broad implications for allied definitions of disability. I am not trying to sustain the impairment/disability distinction defended by social model advocates. Rather, I am using the words to illustrate the difficulty of sustaining a clear-cut dichotomy in conceptual terms. I believe that for analytical purposes it is important to point to several different sources of disability to better illustrate the complexity of the attendant issues and the similar elaborateness of the solutions that must be developed.

not automatically result in a re-creation of democracy. Instead, democratization occurred gradually: elections were held first municipally, then at the state level; and after several years, nationally (Levine, 1999, p.138; Fausto, 1999, p.317). This slow and gradual “opening” (*abertura* in Portuguese), or transition from a military authoritarian regime to a civilian democratic one, had the advantage of avoiding great social upheaval; nonetheless, it did not address existing social inequality, corruption and political patronage (Fausto, 1999, pp.318-19).

Freire’s (1973) analysis of Brazil’s democratic transformation criticized those with power who deployed the politics of assistencialism in an effort to contain social change and to continue treating the nation’s citizens as passive objects (p.14). “The greatest danger of assistencialism is the violence of its anti-dialogue, which by imposing silence and passivity denies men the conditions likely to develop, or to ‘open’ their consciousness” (Freire, 1973, p.15). He saw dialogue as inherent in human nature, affirming that in the proper climate for dialogue “men can develop a sense of participation in a common life” (1973, p.24). Moreover, through assistencialism, individuals are robbed of responsibility, which makes democracy difficult to realize (Freire, 1973, pp.15-16). Freire saw the dearth of dialogue during Brazil’s transition as favoring decrees that made society mute and silent, by which he meant lacking a critical voice and response. In this critical analyst’s view, Brazil was attempting to inaugurate a formal democracy on a “vast lack of democratic experience, characterized by a feudal mentality and sustained by a colonial economic and social structure” (Freire, 1973, p.28). Democracy was an imported idea for Brazil, a superimposed construct for a people with no experience in self-government, offering nothing in the way of guidelines for their first experiments with freedom (Freire, 1973, pp.28-29).

Political participation became relevant again in the mid-1980s when marginalized social groups began to view democracy as more than simply a set of rules governing formal engagement in public life. Instead, these entities increasingly perceived politics as a process of rights-building, in which different social groups should participate (Nascimento, 1995). The re-awakening of Brazilian civil society in the late 1970s revealed the conflicts implicit in a democratization process built on the foundation of “traditional brokered politics” (Levine, 1999, p.153), in which relationships are critical to the conception of social order. New citizenship rights clashed with norms and rules of membership in various social groups, defined by gender, race, political affiliation, occupation and place of residence (Levine, 1999, p.154). However, Levine (1999) has cautioned against rushing to judge the development of citizenship rights in Brazil as inadequate, and argued that observers should be mindful that universal citizenship is a relatively recent attainment, even in the Western democracies (p.157). Within a decade after adopting its new democratic Constitution, Brazil’s government began working on the national policies and actions to incorporate human rights into its national agenda.

The Brazilian government began actively pursuing a human rights agenda in 1996, when the first National Program for Human Rights [Programa Nacional de Direitos Humanos - PNDH], was launched. This initial version was revised and broadened in 2002 as the second National Program for Human Rights. The new effort included protections and guarantees of economic, social and cultural rights (1º Relatório Nacional: Geral §32). The third edition of the Program, PNDH-3, adopted in 2008, consisted of a complex matrix of thematic axes, objectives and more than 500 programmatic actions across all 31 federal Ministries, state agencies, legislative and judicial organizations. PNDH-3 adopted a perspective of universality and stressed the interdependence of rights and their

implementation, envisioning joining the implementation efforts of multiple Ministries and agencies (1<sup>o</sup> Relatório Nacional: Geral §33). The 11<sup>th</sup> National Conference on Human Rights, dedicated to the 60<sup>th</sup> anniversary of the Universal Declaration on Human Rights, served as the foundation for PNDH-3. Some fourteen thousand people from civil society and government agencies were involved in local, regional and state-level Conferences on Human Rights to generate input for the National Conference on the topic of human rights (1<sup>o</sup> Relatório Nacional: Específico §40). PNDH-3 incorporated policies and programs specific to the disabled population, but still lacked accountability yardsticks that would enable poor and marginalized populations to take full advantage of their citizenship rights.

Arguably, the greatest challenge posed to Brazilian democracy is the universal application of citizenship rights (Levine, 1999, p.156). The neoliberal emphasis on ensuring the economic efficiency of healthcare and social security since the 1990s has generated a damaging attitude toward people with impairments in Brazil. As in the case with poor and marginalized people, the wider society views those with impairments as unproductive burdens, unemployable and incompetent, and as such, unworthy of equal rights. The failure to extend rights universally and the decision to tie them to specific situations of competency and employability weakens the foundations of democracy (Levine, 1999, p.156-157). Many young Brazilians consider rights as something to be earned by conforming to social norms, rather than as ensured by birth: “citizenship does not confer rights, rather having rights defines being a citizen” (Levine, 1999, p.156), thus suggesting a temporary and conditional conception of rights. In the case of disabled people, this conceptualization implies they must effectively earn their rights by meeting social expectations in education, employment, and social life. In the next section I argue that CRPD and its ratification by Brazilian legislative and

executive powers has been an important milestone in beginning to shift these societal perceptions and values.

### **Struggle for disability rights**

Brazil was slower than many European countries to address the issue of disability rights (Araújo, 2001). Before the nation's 12<sup>th</sup> Constitutional Amendment of 1978, disabled people received no attention in Brazilian legislation. 1979 marked a breakthrough in the political mobilization of disabled Brazilians and by 1984, the population had its own organized social movement (Lanna Júnior, 2010, p.33). This process was accelerated by the fact that the UN declared 1981 the "International Year of People with Disabilities," helping to bring visibility to the issues of injustice faced by disabled people. The subsequent UN adoption of the World Program of Action concerning Disabled Persons in 1982 and the declaration of the UN Decade of Disabled Persons 1983-1992 also aimed at sensitizing populations to the rights of disabled people in Brazil. However, it was not until its 2008 ratification of the CRPD that the Brazilian state assumed formal responsibility for promoting and guaranteeing the rights of its disabled citizens. While some government officials suggested that ratification of the Convention would bring "immediate results" in Brazil (Convenção, 2010, p.9), the history of struggle of Brazilian disabled people for their rights suggests otherwise. Interviews with several of Brazil's disability movement leaders testify to the amount of persistent hard work that occurred over a long period to attain significant change in social attitudes toward disabled people as well as to obtain improvements in their living conditions.

Brazil signed the Convention and its Optional Protocol in March 2007, affirming its intent to ratify both. The nation formally adopted it in July 2008, and the Convention assumed the status of a

constitutional norm. With strong support from President Luiz Inácio Lula da Silva and pressure from the disability movement activists, no legislators voted against the adoption in either house of the legislature<sup>4</sup>. Many CSOs were also active in raising legislator awareness of the issue and its importance through public campaigns,<sup>5</sup> which helped to mobilize the votes. Disability advocacy organizations have been active participants in deliberations concerning specific policies and actions to implement CRPD aims since its ratification. The new approach was incorporated in the state's more comprehensive and longer-term human rights plans and programs: PNDH-3, mentioned previously, and Plan 2022.

In 2010, the government adopted Plan 2022, which strategically outlined the goals and objectives of the Federal Administration and the Brazilian society. The purpose of Plan 2022 was to promote the full realization of rights for all citizens by 2022. The year 2022 is significant because it is the year Brazil will celebrate its Independence bicentennial. Plan 2022 sought not only to assure accomplishment of equal rights for both disabled and nondisabled people, but also to ensure specific rights for disabled people that make it possible for them, whatever their impairment, to enjoy a full life (1º Relatório Nacional: Geral §73). Ambitious and comprehensive, Plan 2022 was carefully negotiated with many politicians across political parties to gain wide support for its 150 goals and objectives. However, it lacked accountability mechanisms and nearly two years after its enactment,

---

<sup>4</sup> When passed in July 2008 by the Brazilian legislature, the UN Convention became the first international human rights treaty approved in Brazil with a required quorum (three-fifths majorities in each house—House of Representatives and Senate).

<sup>5</sup> *Assino Inclusão* (“I subscribe to inclusion” in Portuguese, <http://www.assinoinclusao.org.br>) is one of the mantras of the social movement for disability rights in Brazil. In 2007, ten local CSOs joined their efforts to work with legislators and other civil society organizations to press for passage of the CRPD. The *Assino Inclusão* movement possesses both technical qualifications (some of the organization representatives participated in the deliberation process of the CRPD) and political qualifications, being capable of bringing together activists, lawyers and lawmakers.

an online search of governmental documents, webpages, and media webpages, revealed no formal updates or public statements of progress towards the adopted targets.

In sum, the struggle for citizenship rights in Brazil has grown since the military regime ended, and many disabled and nondisabled Brazilians have been and remain active in this ongoing effort. As the nation's first legally binding international instrument, the CRPD potentially could serve as a transformative force in the lives of all citizens with impairments in Brazil. In any case, the Convention surely helped an already growing disability rights social movement formalize and legitimize its aims, and it put disability justice on Brazil's national agenda for the first time. The nation's implementation of the CRPD will be a complex and long-term process involving many stakeholders, and, hopefully, the development of novel ways of designing and implementing policies and securing collaboration among civil society groups and the state. To be successful, this endeavor needs to ensure that transparency and accountability mechanisms are in place to enable civil society to participate in and to monitor the conception and implementation of targeted social policies.

### **Examining rights-based policies and advocacy organizations' claims**

Brazil's recent rights-based policies and CSOs' claims are examined in this section to evaluate the degree to which these efforts have contributed to a more inclusive citizenship and a more robust democracy.

The arguments concerning the complex nature of state-civil society relations offered by several scholars (Dagnino, 2002; Held, 1996; Parekh, 2004) help dispel simplified contentions that democracy can be located with assurance in one or the other realm. Brazil is "an interesting setting for understanding the possibilities for democratic transformation," (Baiocchi, Heller & Silva, 2011,

p.7), and despite the nation's authoritarian legacy and dysfunctional institutions, its civil society organizations have challenged elite domination of the nation's political space. Baiocchi et al. (2011) explain how civil society has helped in the effort to "democratize democracy in Brazil" (p.8), contributing to increasing recognition that "there is no single model of democracy" (p.159). From the perspective of disability rights-related policies and claims, I argue that, drawing on Dagnino (2002) and Held (1996), both state and civil society are important in the creation and institutionalization of democracy in Brazil. In what follows, I show that Brazil's national rights-based policies can be at times both inconsistent and ambitious; lacking clear articulation of the principles on which they are based. Most importantly, they lack accountability and evaluative mechanisms. Civil society's role in pressing for more accountability and participation in these domains is therefore crucial.

### **Government's disability rights-based policies**

The Secretariat for Human Rights compiled Brazil's disability rights-related laws, policies and programmatic actions in a National Report [Relatório Nacional] prepared at the beginning of 2011. In April of 2011, the government publicized a belated draft report for 2008-2010 concerning the progress made in implementing the Convention, inviting representatives from civil society organizations and disabled citizens to contribute documented evidence and suggestions, to be analyzed and possibly incorporated into the final national report for the UN. In May 2012, a year after the first draft was publicized, the nation submitted a consolidated final report to the UN, but its contents were not released to the public until later. For that reason, my analysis draws on the draft of the National Report, first presented in April 2011.

The authors of the 2008-2010 report distinguished between short, medium and long-term strategies to promote the rights of Brazil's disabled population. The nation's short-term strategy focuses on three main goals to assist disabled people: first, developing policies for basic healthcare; second, effectively implementing norms that would foster access to the job market and public services; and third, adopting measures to ensure access to media and means of communication. For example, to foster the employability of disabled people, the government has emphasized vocational training. Nonetheless, while such training is important to jumpstart the employment of disabled people, it cannot substitute for the provision of a solid educational foundation on which the government decided to focus as a one of its medium-term goals. While the report goes into great detail concerning the various agencies and programs in place to promote the employability of disabled youth and adults, it says nothing about specific legislation, policies and actions designed to encourage entrepreneurship among members of this population. Fostering entrepreneurship would appear to be a feasible alternative to help lower the traditionally high unemployment rate among people with impairments, yet, to date, entrepreneurship is neither encouraged nor support for people with impairments.

The nation's medium-term policy implementation strategy calls for the consolidation of inclusive education policies for disabled people and the development of programs to remove barriers that hinder disabled citizens from fully participating in public and political affairs. The authors of the CRPD saw enhancing the participation of disabled people as a top priority in securing their rights, especially their political participation. Advocacy organizations that work with this population on a daily basis consider promoting such engagement as the foundation on which to build other rights. Thus, they contend that delaying the removal of barriers that hinder political involvement may defer

the possibility of achieving full citizenship. More importantly, the postponement of guaranteeing the effective right to education contributes to the social injustice disabled youth and adults face. Low educational attainment affects employment opportunities for disabled people (Reicher & Atalla, 2011, p.7).

The National Report also postponed the creation of information systems and identification of indicators that would measure the effects of enacted policies for the benefit of disabled people. That stance implies that the outcomes of short-and medium-term policy actions will not likely be measured, tracked and reported. Conducting and disseminating research on the dimensions of disability injustice would certainly not only make the federal, state and municipal policies more effective, but also empower disabled people in their continuing struggle for justice. Moreover, such action would help put disability rights more squarely on the nation's scholarly research agenda, which to date, has not occurred to any degree (Lanna Júnior, 2010, p.12). By prioritizing and sponsoring research on disability justice, the state may not only promote human rights and potentially develop more effective policies, but also eventually prompt a broader change in attitudes in Brazilian culture toward citizens with impairments.

In analyzing the strategies pursued by the government in promoting rights for disabled people, it seems that the ultimate goal is to achieve equality of status through prioritizing their access to basic healthcare, employment, education and political and social engagement. The National Report's lack of a detailed accounting of adopted policy actions, including increased access for disabled people to education, healthcare, social security and employment has led many to question the utility of pursuing these actions, since no accountability and evaluative mechanisms have been built into their implementation. In partial response to this concern, the Brazilian Senate ordered a

survey of the opinions and perceptions of disabled people concerning their rights, living conditions and policy priorities in late 2010.<sup>6</sup> That effort revealed that out of more than 1000 people interviewed across Brazil, 77 percent considered their rights infringed upon. The combination of inadequate empirical evidence concerning the purpose of policy actions taken to date, coupled with reports from disabled people concerning ongoing discrimination provide advocacy groups with arguments for more intensive and more carefully evaluated public activities on behalf of disabled people.

While Brazil has recently enacted extensive legislation concerning disabled people, its public policies continue to be critiqued as lacking a multidimensional view of the challenges that populations with impairments experience. The advocacy organizations leaders I interviewed all agreed on the nation's need to devise and carry out policies targeted to impaired populations collaboratively.<sup>7</sup> That is, these leaders argued that such efforts should not be designed and implemented by any single sector or Ministry, but include the active engagement of all affected parties including civil society entities, all relevant government Ministries and for-profit institutions.<sup>8</sup> Moreover, a continued lack of accountability mechanisms in policies concerning disabled people, contributes to their persistent ineffectiveness. On the receiving end, public policies do not reach many disabled people, which is a fundamental condition necessary to combat exclusion.<sup>9</sup> While

---

<sup>6</sup> The survey has been retrieved from <http://www.ibdd.org.br/noticias/noticiaspesquisa%20data%20senado%20ibdd.asp>.

<sup>7</sup> Personal interviews conducted with leaders of disability-related CSOs in July-August 2011.

<sup>8</sup> Personal interviews conducted in July-August 2011.

<sup>9</sup> Personal interviews conducted July 14 and August 17, 2011.

disabled people are increasingly aware of their rights, they are often unaware of any public programs or agencies operating for their benefit.

In Held's (1996) conception of democracy, decision-making of the least powerful is crucial, and alleviating inequality between the most and least dominant enhances democracy (p.331). Policy-makers can help bring Held's vision into existence by addressing inequality in a more transparent and participatory way. Public policy-making is neither linear nor predictable, and understanding different interests, principles and ideologies is part of operating in the political environment (Percy, 1990, pp.23; 29). Care should be taken not to frame policy as a technical issue; otherwise decision-making could come to be dominated by perceived technical experts.

### **Disability advocacy organizations' claims**

Brazil's advocacy organizations represent and enact diverse missions, constituencies and strategies of social change. Some of these entities have turned to advocacy strategies to secure the human and civil rights of disabled people and have sought to empower the disabled populace to take charge and voice their concerns in the political process. Other disability-oriented organizations and groups have sought to provide needed services when the state has not done so. In general, there is little cooperation among those CSOs advocating on behalf of disabled people and those seeking to provide disabled individuals with needed services.

Since Brazil's ratification of the Convention in 2008, militant advocacy-focused groups have criticized their fellow organizations still offering direct services to disabled individuals arguing that such efforts perpetuate assistencialist politics. These activists contend that nongovernmental organizations should take an oppositional stance to the government rather than continue to provide

assistance that is rightfully the state's responsibility. This criticism implies that some disability rights organizations may speak legitimately for the rights of disabled people, while others may not, since they do not contribute to the empowerment of this population, and do not seek principally to educate them about their rights.<sup>10</sup> This rhetoric views advocacy as the only legitimate strategy for the disability rights movement.

Advocacy is relatively new in the Brazil's disability rights movement, dating back to 1979 when the movement emerged. In many cases it started as self-advocacy, and in others it has been carried out by others (family members, friends, professional advocates or organizations) acting on behalf of people with impairments. As several interviewed leaders of civil society organizations noted, it is costly to get involved in advocacy and maintain full-time staff dedicated to it. This difficulty encourages some advocacy organizations to form networks and alliances to monitor public policies and legislation approval to ease the burden of any one single entity bearing significant costs. Advocacy organizations' central focus is "the transformation of social problems into public issues and campaigning around those issues to influence public policy or private behavior, whether at the local, national, or transnational level" (Lavalle, Acharya, & Houtzager, 2005, p.955). Nonetheless, as Lavalle et al. (2005) have argued, both advocacy and nonadvocacy organizations participate in the policy process (p.958). If the ultimate goal of the disability rights movement is to secure equal rights for all of Brazil's disabled citizens by influencing public policies, disability rights advocacy organizations may need to join nonadvocacy organizations to facilitate the exchange of ideas and policy discussions.

---

<sup>10</sup> Personal interview conducted August 17, 2011.

Disability advocacy organizations have typically advanced their justice claims by highlighting the importance of effective opportunities for political participation by disabled people. As one disability rights activist stated in an interview, “Until we have effective participation [in public spaces], it will be difficult to change the rules of the game. It’s hard to effectively promote changes to improve life conditions of people with disabilities while they are not present in decision-making processes.”<sup>11</sup> The political participation of millions of disabled people is likely to be undermined by illiteracy. For example, in the city of São Paulo, the largest city in Brazil, 22.7 percent of disabled people are absolutely illiterate, compared to 3.3 percent among nondisabled populations.<sup>12</sup> These realities need to be taken into consideration when trying to encourage political participation by disabled people. A nonadvocacy nongovernmental institution that works directly with disabled populations in adult literacy programs should be seen as a partner to an advocacy organization that intends to promote active political participation. Both institutions create enabling environment for disabled people to shape and enjoy their opportunities in life.

Both advocacy and nonadvocacy organizations employ a range of strategies in addressing disability injustice. The CRPD embraces the view that individuals with impairments are not “problems to be fixed,” but individuals with rights to participate as active members in society and to enjoy the full range of their rights (UN, 2006). This stance slowly became the focus of Brazil’s disability advocacy and nonadvocacy communities, as they aligned their rhetoric with the new approach. If the 1988 Constitution mainly guaranteed social security benefits to poor, disabled and

---

<sup>11</sup> Personal interview conducted July 14, 2011.

<sup>12</sup> Retrieved from the Portal of the Municipal government of São Paulo, [http://www9.prefeitura.sp.gov.br/sempla/mm2/mapas/intro\\_5.pdf](http://www9.prefeitura.sp.gov.br/sempla/mm2/mapas/intro_5.pdf).

senior citizens (Constituição, 2008), the subsequent legislation and policies from the 1990s-on began addressing the economic, social and cultural rights of disabled populations.

To summarize, if successfully implemented, government policies focused on enhancing the status of disabled Brazilians through promoting equal access to basic healthcare, employment, and education, will allow them the same level of access to rights as nondisabled citizens. However, equal access to these resources may or may not affect disabled people's effective opportunities in life. Here, disability advocacy organizations' justice claims and actions are complementary to the government's steps in improving the lives of the people currently worse off.

### **A new perspective on Brazilian disability citizenship?**

This section explores the possible emergence of a new framework for Brazilian citizenship as a result of the nation's changing disability rights policies and the ongoing advocacy efforts of disability rights organizations. I begin with the basic dimensions of citizenship articulated by Abowitz & Harnish (2006), "membership, identity, values, and rights of participation" (p.653), contextualizing those characteristics in the lived realities of Brazil's disabled citizens.

#### **Membership**

While any person born in Brazil is formally considered a citizen, in practice social hierarchies and institutions exclude some groups from being full members of political and economic society. As noted above, the full inclusion of disabled people is challenged by a broadly held view that links citizenship to productivity, which undermines the universal extension of rights to all citizens (Levine, 1999). The disability rights movement and international initiatives, such as the

CRPD, pressed the Brazilian government to embrace equal rights for disabled citizens and to advance anti-discriminatory protections. As one disability-related CSO leader declared, “for changes in public policies to occur, the disability rights movement has to become a united pressure group, because governments deliver outcomes only under pressure.”<sup>13</sup>

In Brazil, several of the advocacy organizations leaders that I interviewed conceptualized social justice in terms of equal rights and membership for disabled people as citizens, not only formally, but also substantively. One interviewee referenced cases in São Paulo in which intellectually impaired children’s access to education has been long compromised as they have been denied enrollment in public schools. Accordingly, the organization has sought to pressure the Secretariat of Education to secure change.<sup>14</sup> Echoing these experiences, another interviewee noted, “the issue of rights of disabled people is an exclusion from citizenship of any Brazilian, because in daily reality it seems like they are not part of the system.”<sup>15</sup>

Membership is a critical dimension of democratic citizenship. Brazil’s disability rights movement has pushed for social inclusion and possibilities to exercise rights, since differences in power result in asymmetrical access to resources and to opportunities in society. Effective membership helps to legitimize the position of advocacy and self-advocacy in promoting disability justice. Nancy Fraser (2010) has suggested there is an important connection between membership and justice, and if disabled people are not considered members of the political community, they “become objects of charity or benevolence (. . . ) [and] non-persons with respect to justice” (p.20).

---

<sup>13</sup> Personal interview conducted August 11, 2011.

<sup>14</sup> Personal interview conducted July 12, 2011.

<sup>15</sup> Personal interview conducted July 14, 2011.

Fraser (2010) saw political membership as a key means to address assistencialism. The CSOs that advocate on behalf of disabled people in Brazil also echo her claims.

### **Identity and Values**

The right to be different with respect to the norms of the dominant community, while still preserving one's right to belong and to participate in democratic processes, is central to the current struggle to define citizenship (Abowitz & Harnish, 2006, pp. 669-670). In Brazil, this is particularly important for Deaf people who struggle to assert their identity and to employ sign language. The dominant culture is a hearing one, for decades Deaf people have been forced to learn to speak and strongly discouraged from communicating in sign language at home, or with their peers. Blind Brazilians also have to pressure the government for their access to cultural resources in Braille, audio-description and other technologies. The ratification of the CRPD gave new force to the claims of equal worth of diverse identities, calling for laws and policies that explicitly take difference into account.

The Convention is helping Brazil's Deaf people to promote society's recognition of their right to conduct their lives as they choose. Some municipal governments have invested in bilingual (Portuguese and Brazilian Sign Language) elementary schools, in which children and teachers are immersed in a bilingual cultural environment. Some have argued this sort of cultural immersion will create a new generation of Brazilians with less prejudice toward difference and who will be more culturally sensitive.<sup>16</sup> Citizenship that promotes social justice goes beyond tolerance and respect and promotes the view that the rights of people with impairments are collective rights. As Brazil's

---

<sup>16</sup> Personal interviews conducted July 26, 2011.

society advances in ensuring the citizenship rights of its people generally, it will advance disability rights as well.<sup>17</sup>

## **Participation**

The importance of engagement emerges across the discourse of many disability rights organizations. Reicher and Atalla (2011) state that “improvement in the quality of life of people with disabilities is directly related to broadening their participation in society” (p.3). As one disability-related CSO leader pointed out, “people with disabilities need to believe in themselves, to strengthen their self-esteem so that they take on this new position, which is a matter of social justice, having equal rights, making their own choices instead of others choosing for them, having the freedom and autonomy of decision-making, with responsibility for the choices made.”<sup>18</sup> These quotations evoke a Freirean spirit and underscore the importance of agency and empowerment in building full citizenship for disabled people. While disabled people’s participation is crucial for securing full citizenship, it is important to acknowledge that low educational attainment among these citizens is a key factor in their weak participation. In 2010, 61.1 percent of the disabled population, ages 15 and older, had incomplete elementary education or no education at all.<sup>19</sup> A few years of schooling are hardly sufficient to understand the language of official documents, which leads in turn to low political literacy of disabled Brazilians.

---

<sup>17</sup> Personal interview conducted July 26, 2011.

<sup>18</sup> Personal interview conducted July 12, 2011.

<sup>19</sup> General characteristics of population from 2010 Census retrieved from [http://www.ibge.gov.br/home/presidencia/noticias/noticia\\_impresao.php?id\\_noticia=2170](http://www.ibge.gov.br/home/presidencia/noticias/noticia_impresao.php?id_noticia=2170)

The model of citizenship for people with impairments in Brazil may be viewed as comprised of full and effective membership, right to diverse and equally valued identities and effective right to participation. The disability rights movement seeks to combat discrimination and promote a more inclusive society with the help of laws and social policies. To improve the effectiveness of promoting disability rights, Brazilian disability-related CSOs need to engage in a broader dialogue and deliberation by collaborating with a wider set of actors in society. If disability rights are not a special interest, as MacIntyre has suggested, they are "...the interest of the whole political society, an interest that is integral to their conception of their common good" (cited in Shakespeare, 2006, p. 67). Shakespeare (2006) has strongly contended that "supporting positive social relationships between disabled and nondisabled people and recognizing the beneficial roles of solidarity and mutuality are both vital to the flourishing of disabled people" (p.199). If disability citizenship is conceived and articulated in these broader terms, it may be easier to promote it as a common goal rather than as an aspiration for only a particular segment of society.

### **Conclusions**

This article has argued that realization of human, civil, political and social rights for Brazilians with impairments cannot be successfully carried out by the state or civil society entities alone—their cooperation is crucial to any successful realization of this aspiration. The Brazilian state has now incorporated disability rights into its larger national human rights plans and policies, a necessary and significant step. Next, the state actors responsible for the promotion of disability rights should engage more with the experiences brought to the table by disabled people themselves and by the CSOs that work with them on a daily basis. Better conceived and implemented public policies

for disabled people will help promote the full realization of, not only their citizenship rights, but also of the rights of nondisabled citizens, and support the development of a stronger democracy in Brazil.

Rights are crucial for building citizenship for disabled Brazilians, and ensuring their attainment will help address long-existing concerns about the relative 'invisibility' of the perspectives and interests of people with impairments in the nation's social, economic and political arenas. This seems to be particularly true in developing countries such as Brazil with high illiteracy rates and poverty among its people with impairments. This article has argued that in conditions of poverty and social inequality, preparing active citizens for effective democracy occurs during the course of empowering disadvantaged people to address the inequality in which they are living. While all those I interviewed agreed that active citizen participation is fundamental to promote justice, the disability rights movement will continue to need to find modes of engagement that promise benefits to all citizens with impairments. For the development of a more inclusive democratic society to occur, common goals centered on a shared conception of citizenship and social justice should be established, by including previously excluded voices and perspectives.

## References

- 1º Relatório Nacional da República Federativa do Brasil sobre o cumprimento das disposições da Convenção sobre os Direitos das Pessoas com Deficiência 2008-2010 [ 1<sup>st</sup> National Report of the Federal Republic of Brazil on the compliance with the dispositions of the Convention on the Rights of persons with Disabilities 2008-2010]. Retrieved from <http://portal.mj.gov.br/sedh/corde/relatorio.pdf>.
- Abowitz, K. K. & Harnish, J. (2006). “Contemporary Discourses of Citizenship,” *Review of Educational Research*, Vol. 76, No. 4, pp. 653-690. doi: 10.3102/00346543076004653.
- Araújo, L. A. (2001). *A Proteção Constitucional Das Pessoas Portadoras De Deficiência* [Constitutional Protection of the People Bearing Disabilities] 3<sup>rd</sup> ed., Brasília, CORDE. Retrieved from <http://www.mp.rs.gov.br/dirhum/doutrina/id248.htm> .
- Baiocchi, G., Heller, P., & Silva, M. (2011). *Bootstrapping Democracy: Transforming Local Governance and Civil Society in Brazil*. Stanford, CA: Stanford University Press.
- Constituição do Brasil. (2008). [Constitution of Brazil], compiled amendments. Retrieved from [http://www.planalto.gov.br/ccivil\\_03/constituicao/constitui%C3%A7ao.htm](http://www.planalto.gov.br/ccivil_03/constituicao/constitui%C3%A7ao.htm).
- Convenção sobre Direitos das Pessoas com Deficiência: Protocolo Facultativo à Convenção sobre os Direitos das Pessoas com Deficiência [The Convention on the Rights of Persons with Disabilities: Optional Protocol to the Convention on the Rights of Persons with Disabilities]: Decreto Legislativo nº 186, de 09 de julho de 2008; Decreto nº 6.949, de 25 de agosto de 2009 (2010). 2<sup>nd</sup> Edition, Brasília : Secretaria de Direitos Humanos. Retrieved from [http://www.direitoshumanos.gov.br/pessoas-com-deficiencia-1/Convencao%20dos%20Direitos%20Humanos\\_26-7-10.pdf](http://www.direitoshumanos.gov.br/pessoas-com-deficiencia-1/Convencao%20dos%20Direitos%20Humanos_26-7-10.pdf).

- Dagnino, E. (2002). (Ed.) *Sociedad civil, espacios públicos y democratización: Brasil*. [Civil Society, public spaces, and democratization: Brazil] México, México: Fondo de Cultura Económica.
- Fausto, B. (1999). *A concise history of Brazil*. Cambridge, U.K.; New York: Cambridge University Press.
- Fraser, N. (2010). *Scales of Justice: Reimagining Political Space in a Globalizing World*. New York, NY: Columbia University Press.
- Freire, P. (1973). *Education for Critical Consciousness*. New York, NY: Seabury.
- Held, D. (1996). *Models of Democracy*. 2<sup>nd</sup> ed. Stanford, CA: Stanford University Press.
- International Disability Alliance – IDA (2008). *Position Paper on the Convention on the Rights of Persons with Disabilities (CRPD) and Other Instruments*. Retrieved from [www.un.org/disabilities/documents/COP/IDA%20CRPD%20paper.doc](http://www.un.org/disabilities/documents/COP/IDA%20CRPD%20paper.doc).
- Lanna Júnior, M. C. M. (2010). *História do Movimento Político das Pessoas com Deficiência no Brasil*. [The History of the Political Movement of People with Disabilities in Brazil] - Brasília: Secretaria de Direitos Humanos; Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência.
- Lavalle, A. G., Acharya, A., & Houtzager P. P. (2005). “Beyond Comparative Anecdotalism: Lessons on Civil Society and Participation from São Paulo, Brazil,” *World Development*, Vol.33, No. 6, pp. 951–964. doi: 10.1016/j.worlddev.2004.09.022.
- Levine, R. (1999). *The History of Brazil*. Westport, CT: Greenwood Press.
- Nascimento, E. P. (1995). “Estado e Sociedade no Brasil: Novos Padrões de Relacionamento?” [State and Society in Brazil: New Patterns of Relationship?] Retrieved from <http://www.cjf.jus.br/revista/seriemon04.htm>.

- Parekh, B. (2004). Putting Civil Society in Its Place. In M. Glasius, D. Lewis, & H. Seckinelgin (Eds.), *Exploring Civil Society: Political and Cultural Contexts* (pp.15-25). London; New York: Routledge.
- Percy, S. L. (1989). *Disability, Civil Rights, and Public Policy: The Politics of Implementation*. Tuscaloosa, AL: University of Alabama Press.
- Pothier, D. & Devlin, R. (Eds.). (2006). *Critical Disability Theory: Essays in Philosophy, Politics, and Law*. Vancouver, BC: UBC Press.
- Reicher, S. & Atalla, R. (2011). *A Convenção da ONU sobre os direitos das pessoas com deficiência – status de implementação nos países do G20*. [The UN Convention on the Rights of Persons with Disabilities – status of implementation in G20 states]. Retrieved from the Konrad Adenauer Stiftung Foundation's website [www.kas.de/wf/doc/4434-1442-5-30.pdf](http://www.kas.de/wf/doc/4434-1442-5-30.pdf).
- Shakespeare, T. (2006). *Disability Rights and Wrongs*. New York, NY: Routledge.
- United Nations - UN. (2006). "Convention on the Rights of Persons with Disabilities and Optional Protocol." Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.