

# DEMOCRATIC JUSTICE FOR BRAZILIANS WITH IMPAIRMENTS

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## ABSTRACT

For decades, Brazilians with impairments have not been able to enjoy full citizenship rights because of the existing oppressive structures in their society. This study examines comprehensions of justice for citizens with impairments in Brazil and what the implications of those perspectives may be for policy arguments and for social change. The principal sources of these justice-related outlooks are three key stakeholder groups: policymakers, disability nongovernmental organizations (NGOs) and people with impairments.

The analysis is organized as follows. First, I provide an overview of the study, its aims and significance and research questions. Second, I discuss the theoretical foundations of the inquiry, focusing on debate among democratic theorists on the meaning of citizenship and social theorists on the significance and goals of social justice, as well as the key debates among disability theorists on the purport of disability, oppression, emancipation and social inclusion. Next, I describe the research design and methods employed in this effort, explaining the rationale behind my choice of a qualitative approach and offering details concerning the study's data collection, analysis and interpretation. Fourth, I summarize the issues and tensions implicit in Brazil's practices and institutions as these relate to the nation's disabled citizens. Fifth, I discuss the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which has helped an already growing social movement in Brazil formalize and legitimate its aims and place disability justice on the national agenda. Sixth, I explore the major conceptions of justice expressed by disability NGOs and analyze what these views suggested for efforts to secure full citizenship for the disabled in Brazil. Next, I explore the conceptions of impairment, disability and justice as imagined and lived by Brazilians with impairments. Specific ideas and conceptions of disability informed the understandings of justice of the individuals with impairments whom I interviewed. Finally, I provide an interdisciplinary interpretation of the research findings, in which I create a dialogue among different perspectives in order to outline a new understanding of justice for people with

impairments and the social change needed to reach that aspiration. After discussing the insights of different stakeholders on justice, I share my recommendations for further research.

*Keywords:* social justice, disability, impairment, democracy, social policy, Brazil.

Dedication

For Mauricio

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## **Chapter 1**

### **Introduction**

Involvement with disability rights among individuals who are not impaired usually arises from their having a personal tie to someone who has impairments. After almost five years working in non-governmental organizations (NGOs) concerned with disability rights, I have the honor of many such connections in São Paulo, Brazil. Most of my friends and work colleagues who are impaired are middle-class individuals with college or even graduate degrees, which is not typical of the majority of Brazilians with impairments. In general in Brazil, there is a significant overlap among impairment, disability, poverty and illiteracy, leading to weak political and social participation and reduced opportunities to improve one's life prospects. Besides personal connections, I am also strongly drawn to pursue issues that relate to justice and creating a better society for everyone.

This dissertation's central concerns are social justice, democratic citizenship and disability and this introductory chapter has four primary aims. I first share my problem statement. Thereafter, I describe my research purpose and its significance. Third, I outline my research questions. Finally, I review the study's organization.

#### **Statement of the Problem**

For decades, Brazilians with impairments have been denied full citizenship rights by their country's broader society. Prior to recently enacted rights-based policies, a politics of assistencialism served as a rationale in Brazil for public support provided to the poor and disabled. Assistencialism was predicated on a 'charity for the afflicted' mindset and produced

dependency among its recipients while doing little to address the root causes of inequality marginalized Brazilians confronted on an everyday basis. Entailing tutelage of marginalized citizens, the assistencialist perspective constrained their freedom to make decisions and to assume responsibility for those choices. Paulo Freire (1973) criticized this form of politics, stressing the dangerous implications of, “the violence of its anti-dialogue, which by imposing silence and passivity denies men the conditions likely to develop or to ‘open’ their consciousness,” making democracy difficult to realize because a substantial share of the nation’s population lacked a critical voice (pp.15-16). “Assistencialism” created strong resistance to advocates among disability rights in Brazil as the movement became more organized (Lanna, 2010).

In light of this difficult past, the current conceptions of justice and accompanying rationales that people with impairments hold in Brazil emerge as a critical question. Since research on disability rights in Brazil is incipient (Lanna, 2010, p.12), this question demands deeper exploration. Western disability studies scholars have debated the appropriate boundaries of their domain of inquiry for many years (Linton, 1998b; Thomas 2007), the advantages and limitations of the social model of disability (Corker & French, 1999; Schillmeier, 2010; Siebers, 2001; Tremain, 2005), bioethics (Block, 1997; Scully, 2008; Tremain, 2005) and the meaning of justice for disabled people (Nussbaum, 2006; Sen, 2004). By comparison, there has been relatively little scholarly research on disability and justice in contemporary Brazilian society and such inquiry as has been undertaken typically has addressed a specific right, such as education, work conditions, accessibility or medical services.<sup>1</sup>

Brazilian scholars have examined the Law of Quotas (a compulsory percentage of employees with impairments applied to companies with 100 employees or more) and its effect on employers and the employability of professionals with impairments and analyzed social representations in special education, among other topics (see, for example, Amaral, 1984; Araújo, 2001; Bergamo, 2009; Do Carmo, 1989; Maciel, 2000). These empirical studies reflect well the issues of social inequality and challenges faced by Brazil's policymakers on all levels. However, more fundamental claims concerning who qualifies for citizenship and how that conception has been constructed and enacted as well as attainment of a robust understanding of the cultural, social and political barriers that limit its exercise, have so far gone unaddressed. Enforcing compliance with a few laws and policies in a top-down manner without stimulating cultural change in prevailing public norms and attitudes is unlikely to prove an effective strategy to secure rights for the country's disabled in the long-run.

Despite the fact that there are many theories of social justice today, the majority of them do not address the issue of impairment and disability. As Nussbaum has rightly pointed out, most Western theories of justice neglect this population: "Facing it well will require not simply a new application of the old theories, but a reshaping of theoretical structures themselves" (Nussbaum, 2006, p.2). This view holds true in Brazilian disability scholarship as well as in related Western research. To my knowledge, no theoretical approaches to justice have been developed in Brazilian academic inquiry to address this population. Exploring conceptualizations of social justice and imagining how they contribute to thinking about potential Brazilian public policy may be helpful in identifying common issues and questions that both should address, thereby helping to bridge the gap between theories of justice and their societal implications for the nation.

This research examines contemporary public and private discourses to build a multi-faceted understanding of how different actors in Brazil perceive and enact justice, citizenship and disability. While, as I have noted, inquiry concerning disability issues is a relatively recent development in the nation, Brazil offers a rich case of ongoing efforts by civil society organizations to realize full citizenship rights for this population. These groups have for some years now sought to translate the provisions of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) into laws and effective public policies and to develop popular support for joint public-private sector efforts to carry them out. Meanwhile, the ideas and experiences articulated by Brazil's people with impairments are influenced by many contextual factors, including attitudes and practices of the wider society that may be enabling or disabling. These views complement the formal conceptions articulated in public policies and civil society organization efforts.

This section clarifies the terminology I use throughout this study. I acknowledge and respect the choices that disabled people make in choosing how best to describe their identity and experiences: some people prefer to use the term 'person with disability' while others employ the phrase 'disabled people.' I came across both terms in the literature. Yet others, with hearing impairments, may choose to describe themselves as deaf instead of hearing impaired. The major disability movement organizations in Brazil and those I interviewed preferred 'persons with disability,' or *‘pessoas com deficiência’* in Portuguese, to put people first, before disability, "to humanize the denomination," as Lanna (2010) has described it (p.15). I chose to adopt 'disabled people' throughout this study to point to those with various impairments who are oppressed and discriminated against, or 'disabled' based on their society's dominant values and attitudes and the oppressive structures that render them

marginalized and powerless. I use the terms ‘impairment’ and ‘disability’ advisedly, bearing in mind a conceptual link between them; impairment may or may not be tied to disability and social oppression, but there is no disability without impairment.

Impairment and disability have often been conceived in terms of the biological features of a person that deviate from a society’s culturally established conception of normality—physical, intellectual and emotional attributes. 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 concepts to illustrate the difficulty of establishing 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 illustrate the complexity of the attendant issues and the similar elaborateness of the solutions that must be developed. I will further treat the distinction and the relationship between impairment and disability in Chapters 2, 5 and 7.

### **Significance of the Study**

This analysis brings together different theories and insights to develop an informed discussion of justice and disability in contemporary Brazil. The argument bridges formal discourses and local stakeholders’ understandings of justice related to disability. This qualitative inquiry examines multiple perspectives regarding conceptions of justice for the population with impairments in Brazil, without restricting the analysis to specific rights, such as the right to work, education, transportation, etc. The analysis identifies whether people with impairments are portrayed or conceived by legislators and disability NGOs as otherwise

ordinary individuals whose problems can be “fixed” by better laws and policies. Many of the formal discourses of disability had been internalized and then articulated by the individuals with impairments in the interviews I conducted, in which those with whom I spoke identified themselves as having a “problem.” Understanding disability and justice issues that affect this population can contribute to evening out social, economic, cultural and political disparities and reducing the collective marginalization of this group in Brazilian society. For advocacy organization practitioners, my study augments existing knowledge of how people with impairments are regarded, as these NGOs work with the Brazilian government on periodic reports to the United Nations concerning measures taken to address the nation’s obligations under the UN Convention on the Rights of Persons with Disabilities, UNCRPD (Article 35 of the Convention).

This study also contributes to the existing empirical literature concerning how generated discourses have framed disability in policy agenda-setting dynamics in Brazil and beyond. Since no single factor brings about policy change (Kingdon, 1995; Kingdon, 2001; Percy, 1989), exploring the perspectives of various stakeholders concerning what constitutes just conceptualization and treatment of the disabled may help to generate valuable insights into design and implementation of disability policy in Brazil. This analysis may also yield not only a potential theoretical contribution to Brazilian conceptions of justice, impairment and disability, but also help to address the gap between social justice theory and policy applications (see Craig, Burchardt & Gordon, 2008 for further discussion of the gap between social justice theory and social policy). Moreover, the argument explored here may be extended to other socially marginalized groups, such as sexual minorities and the poor. Finally, this study may contribute to a general increase in consciousness of existing

exploitative social relations related to Brazil's disabled citizens, by uncovering these perspectives for the stakeholders I studied.

Brazil's ongoing struggle concerning the rights of people with impairments may potentially spill over into controversies addressing other social and political rights issues, including violence and discrimination against women and black and indigenous persons, among others. It is clear, at least from the point of view of attempts to realize democratic justice, that many efforts should be made to learn the needs and views of those traditionally the target of discrimination. All perspectives are important and through a comparative analysis of findings from the sources of information outlined, several critical viewpoints may be better understood. I regret not being able to represent these populations from across Brazil adequately, but this lacuna can be addressed in future work and doing so may also reveal regional differences. Examining disability and justice discourses across legal and policy acts, for other localities, specific sub-groups and environments can also be addressed through additional research.

### **Purpose of the Study**

This study seeks to understand conceptions of justice for citizens with impairments in Brazil and what the implications of those perspectives may be for policy arguments and for social change. The principal sources of these justice outlooks are three key stakeholder groups: the Brazilian government, disability-advocacy NGOs and people with impairments.

The Brazilian government's official documents I analyze here include the 1<sup>st</sup> National progress report with policy priorities prepared for the United Nations (UN). Examining that

effort provided insights into the views of justice of Brazil's representatives responsible for designing and implementing appropriate policies for this population group. Exploration and critical analysis of the annual reports and websites of key disability NGOs in Brazil as well as interviews with a sample of their leaders yielded an understanding of how they have framed their cause for the broader public. This effort constitutes the second element of my analysis. Third, I explore the understandings of justice articulated by people with impairments. Their perceptions of needed change to advance their justice related claims helped me understand better those who are being represented in disability-advocacy NGO discourses.

This study addresses a particular historical period, geographic location and targeted group of participants. Besides this scope delimitation, financial constraints limited my opportunities to travel and conduct interviews in different locations. I analyzed government documents as well as the annual reports and websites of disability NGOs in Brazil online. The most resource-intensive portion of this study involved arranging in-person interviews with individuals with impairments and NGO leaders. I interviewed 18 individuals as depicted in Figure 1. The majority of my interviewees lived in São Paulo, the largest metropolitan area in Brazil, with a population exceeding 10 million. I share more details concerning my research design and methods in Chapter 3.

*List of 18 interviews conducted in July-August 2011*

<b>Leaders of Disability NGOs</b>
(One representative interviewed from each organization, 7 total)
3IN
CVI Araci Nallin
IBDD – Instituto Brasileiro dos Direitos da Pessoa com Deficiência
Instituto Paradigma
Mais Diferenças
Nosso Lar
RIADIS – Rede Latino-Americana de Organizações não Governamentais de Pessoas com deficiência e suas Famílias

<b>People with Impairments (11 total)</b>
3 individuals with physical impairments
3 deaf individuals
3 individuals with visual impairments
1 individual with intellectual impairment
1 individual with multiple impairments – visual and physical

## Research Questions

I sought to design my research questions so as to reflect the experiences of people with impairments. I also structured my effort to the extent feasible to contribute not only to academic and practical knowledge, but also and most significantly, to Brazil's population with impairments. Thus, the research questions I explored in this study concerned different conceptualizations of justice principles reflected in the work and projects of the Brazilian government, representatives of disability NGOs and people with impairments. The central question and associated sub-questions that underpinned this study, distinguished as recommended by Creswell (2009, p.129), follow:

- How do Brazilians with impairments understand justice?
  - How do they experience disability in their day-to-day lives?
  - What needs to be changed in Brazilian society, in their view, to make it more just?
- What are the foundational concepts of justice on which prominent Brazilian disability NGOs predicate their claims?
  - How are those conceptions reflected in their mission and values?
  - How do they frame the population with impairments in their policy advocacy discourses?
  - Are those narratives consonant with the justice principles they embrace?
- What justice concerns did government representatives address in the nation's UN report and how did those relate to the disabled?

- How do those public officials evaluate the effectiveness of the policies enacted to address the needs of the population with impairments?

These questions address several concerns that Shakespeare (2006) raised some years ago when arguing that solutions for the challenges confronting the disabled are broader than rights alone. Shakespeare (2006) suggested social justice represented a preferable goal to rights attainment for disability movements: “Rights alone will not solve all disability problems” (pp. 198-99). Accordingly, my questions are not tied to particular rights, but rather framed in terms of exploring the conceptualizations of justice that Brazilians with impairments embrace. The queries also offer a critical lens into the barriers existing in society to make it more just, from the perspective of people with impairments. My research concerning disability NGOs and governmental representatives also sought to look beyond specific rights, to ascertain the justice frameworks that these actors enact in their discourses and practices. From the point of view of interdisciplinary study, I see a major creative challenge for my work in developing an ethnography considering the relationships among biological, political, social and ethical processes and integrating various perspectives to understand more completely these alternate perspectives of justice.

### **Chapter overview**

Apart from this introduction, this study is organized into seven additional chapters. I discuss the theoretical foundation of this effort in Chapter 2, which summarizes and examines broad themes in relevant literature (Cooper, 1984 cited in Creswell, 2009, p.28). More

particularly, the chapter focuses on differences among democratic theorists on the meaning of citizenship and among social justice thinkers on the meaning and goals of social justice. Chapter 2 also addresses the key debates among disability theorists on the meanings of disability, oppression, emancipation and social inclusion. The primary concerns explored throughout that chapter's analysis of various theoretical perspectives are, "How are conceptions of justice and democracy reconciled?" and "How are democracy and human rights related?" I also investigate the question, "How are social justice and social policy related and how does each link to the disabled?" This discussion accomplishes several purposes. First, it shares with readers the results of other studies closely related to the one undertaken here, thereby relating this analysis to the ongoing dialogue and debates in the literature (Creswell, 2009, p.25). Second, it provides a framework in which to situate this investigation's research problem, consistent with Creswell's (2009) suggestion for ethnographic studies (p.26). Overall, I have used the conceptual approaches represented in the literature to shape both the questions for investigation and to imagine the scope of change necessary to attain those proposed perspectives (Creswell, 2009, p.62).

Chapter 3 describes the research design and methods employed in this effort. It provides an overview of the components of my analytic and methodological stance in general, explaining the rationale behind my choice of a qualitative approach and offers details concerning data collection, analysis and interpretation and an explanation of the challenges identified and addressed through the specific research strategy adopted. The chapter highlights the importance of context in this study, since environments play a role in shaping individual and group conceptions of justice. The validity of this study was enhanced via a careful analysis of the problem from each disciplinary perspective and evaluating each insight

into it. As this is an interdisciplinary effort, the chapter outlines methods employed from social sciences (interviewing) and the humanities (discourse analysis). The study overall also seeks to integrate theoretical perspectives across several literatures through a series of steps to achieve interdisciplinary understanding of a problem (Repko, 2008, p.247), with an ultimate purpose of creating dialogue and negotiating the differences of meanings of justice for disabled people. That analysis appears in the concluding chapter.

Chapter 4 summarizes the issues and tensions implicit in Brazil's practices and institutions as these relate to the nation's disabled citizens. Brazil's renewed efforts to democratize beginning in the late-1980s did not end inequality and disempowerment of the nation's poor and disabled citizens. The practice of assistencialism has continued to be a rationale for support provided to these two groups long after adoption of the democratic Constitution of 1988. Assistencialism does not address the root causes of inequality that excluded and marginalized groups confront in Brazilian society and those populations continue to experience injustice on a daily basis. The unfairness experienced by disabled Brazilians is a multifaceted phenomenon. Young's (1990) account of oppression is helpful in gaining an understanding of the different situations the country's disabled people experience as a group. The chapter presents empirical data in light of major theoretical debates concerning democracy, human rights and justice and disability, ending with an overview of the dimensions of injustice as reportedly experienced by several disabled individuals.

Chapter 5 discusses the UN Convention on the Rights of Persons with Disabilities (UNCRPD) that potentially could help transform the lives of the disabled in Brazil and worldwide. Indeed, in Brazil, the Convention has helped an already growing social movement

formalize and legitimate its aims and to place disability justice on the national agenda. However, the UNCRPD's scope and potential in securing the human rights of the disabled in the future should not be overestimated. As a negotiated international instrument, the Convention blended a variety of values and perspectives, which resulted, in some scholars' views, in an inconsistency in adopted terminology and overall structure. In practice, this internal inconsistency may complicate implementing the accord as well as make reporting concerning progress in attaining its aims more difficult, as my brief review of the Brazilian situation underscores. The nation's implementation of the UNCRPD will be a complex and long-term effort involving many stakeholders and, hopefully, the development of novel ways of securing collaboration among civil society groups and the state. The nation's government has incorporated disability rights into its larger human rights plans and policies, an important inclusive step. However, the effectiveness of these actions will depend largely on the accountability and evaluative mechanisms built into their implementation and the evidence thus far is not hope inspiring. Moreover, the nation's relatively new human rights policies will be of limited benefit to the development of its democracy if they do not address the deeper injustices confronting the disabled that inhere in prevailing social and cultural attitudes.

Chapter 6 explores the major conceptions of justice expressed by the disabled in Brazil as these could be gleaned from disability NGO reports and websites and interviews with their leaders. I sought to describe what these views suggested for efforts to secure full citizenship for the disabled in Brazil. After providing a brief overview of disability NGOs in Brazil as background, I examined the claims these organizations make concerning the meaning of citizenship for the disabled and how it might most effectively be ensured. My examination of relevant NGO discourses revealed broad adoption of liberal conceptions of justice. In the

chapter's final section I analyze the implications of that stance for social inclusion of Brazil's severely disabled citizens and for development of the nation's democracy. Drawing on Reinders (2000), I argue that the notion of liberal citizenship articulated by the disability rights NGOs in particular cannot provide for inclusion for individuals with severe impairments. Any rationale for social acceptance of this population must ultimately rest on communal values, rather than liberal ones. I offered a hopeful account of one episode provided by one interviewee that suggests that such is surely possible in Brazil in the long run, but public policy and interested NGOs alike will need continuously to make the case in the public square for such an orientation and for why it matters to the nation.

Chapter 7 explores the conceptions of impairment, disability and justice as imagined and lived by Brazilians with impairments. I discuss some conceptions of impairment and disability as these views and experiences set an important context for the emergence and understanding of the views of justice discussed later in the chapter. These notions and experiences are not formed in isolation by factors intrinsic to the individual, but also influenced by contextual influences, such as the values and attitudes of family and loved ones and of wider society that may be enabling or disabling. Ideas and conceptions of disability informed the formation of perspectives of justice that the individuals with impairments I interviewed held. These views of justice reveal diverse notions of what is just as well as a related rhetoric of blame directed at society at large, some people with impairments, and certain medical and educational professionals for the situations in which they are enmeshed.

Chapter 8 employs the theoretical lenses discussed in Chapter 2 and the methodological frame outlined in Chapter 3 to produce an interdisciplinary interpretation of

the study's research findings. I sketch the implications of the understandings of justice analyzed in Chapters 5, 6, and 7 for policy arguments and for social change. The scholarly thought I drew on for this study already contains multiple disciplinary perspectives ranging from political theory, ethical theory, feminist theory and disability theory and policy. My ultimate purpose is not to diminish the differences in these views by focusing on the common ground among them, but rather to create a dialogue among these different perspectives, to outline a new understanding of justice for people with impairments and to describe the social change needed to reach that aim. As social life consists of multiple experiences and perspectives, the democratic view of moral and political judgment is best understood as a product of dialogue in which all those affected have a voice under conditions of equality and mutual respect, and in which, too, people are able to enlarge their thinking (Young, 1997). After discussing the insights of different stakeholders on justice, I share my recommendations for further research to end the chapter and conclude the study.

## Chapter 2

### Conceptual Framework

This chapter summarizes and discusses broad themes in the literature on political theory, justice theory and disability theory to lay the foundation for a critical analysis of social justice and disability rights policy in contemporary Brazil. The principal questions explored here across various theoretical perspectives include:

- Does promoting justice entail promoting democracy?
- How are democracy and human rights related?
- How are social justice and social policy related and what concerns do they share?

I treat each of these matters specifically as they relate to the domain of disability.

This review of recent pertinent literature is organized into four major parts addressing the following topics: Justice and democracy, democracy and human rights, social justice theory and social policy and disability theory. I focus on the existing debate among democratic and social justice theorists on how these may be reconciled, on the goals and meaning of social justice and its links to social policy and on the arguments among disability theorists concerning the meaning of disability, oppression, emancipation and social inclusion. This review of relevant literature not only helps substantiate the need to address the research problem I have outlined, but also has shaped the questions I have asked and the policy changes I ultimately propose (Creswell, 2009).

My study fits in the bodies of literature reviewed below in different ways. First, it fills a specific niche in the scholarly theoretical and empirical literature broadly concerned with social justice, namely, identifying and comparing the conceptions of justice at play in Brazil concerning individuals with impairments. Second, my analysis clarifies how efforts to advance social justice claims have unfolded within a specific set of social policies and what issues and challenges have been encountered in that process. Analysts disagree concerning how most effectively to pursue justice. These disagreements, according to some scholars, generate a gap between theories of social justice and their policy implications. While political philosophers develop conceptions of justice, policy activists often find them useless for their purposes. Instead, they devise policies, many times inconsistent, for the population within society that concerns them most (Craig, Burchardt & Gordon, 2008, p.3).

Third, this study contributes to the scholarly debate concerning the relationship between promoting democracy and implementing an effective human rights regime within nations. There is a significant overlap between citizenship rights as theorized by T.H. Marshall (see, e.g., Shafir, 1998, pp.93-112) and human rights as discussed later in this chapter. Assuming Hakopian (2007) is correct that, “full citizenship is an essential ingredient in a quality democracy” (p.20), I argue that implementing human rights as an interdependent framework of civil, political, social, economic and cultural rights advances full citizenship and a more robust democracy.

## **Justice and Democracy**

While an undemocratic but just society is surely conceivable, many would nonetheless agree that democracy is the best way to sustain efforts to secure social justice. On the other hand, democratic decision-making does not always deliver just outcomes. Indeed, the relationship between justice and democracy is complex and too little explored (Dowding, Goodin & Pateman, 2004; Gould, 2004; Shapiro, 1999). As Shapiro (1999) remarked more than a decade ago, “the question of what should be the relations between the demands of justice and the practices of a democratic polity remains remarkably unexplored” (p.5). Dowding, Goodin and Pateman (2004) also have suggested that political philosophy has focused on justice and democracy separately, but rarely on both concerns simultaneously (p.1). This orientation arose partly from disciplinary divides and differences, in which research on democracy and power was centered in political science departments, while inquiry into justice more often was the province of philosophy faculty (Dowding, Goodin & Pateman, 2004, p.3). Furthermore, while many theorists of justice at least implicitly prefer democracy, democratic theorists, “have been remarkably silent about justice” (Dowding, Goodin & Pateman, 2004, p.6).

I have organized my accounting of the ongoing discussion among theorists concerning the relationships among different interpretations of ‘justice’ and ‘democracy’ into three broad narratives. First, I examine the argument that democracy plays an instrumental role in attaining justice (Arneson, 2004; Dowding, 2004; Goodin, 2004; van Parijs, 1996). In this view, democratic processes do not guarantee just outcomes, and to justify democratic choice making, scholars of this persuasion suggest criteria of justice independent of those processes.

Second, I analyze the arguments of those who claim that democracy is intrinsically just (Cristiano, 2004; Cristiano, 2008; Dahl, 1991; Griffin, 2003; Valentini, 2010). These authors do not appeal to any independent standard of justice to judge the justness of democratic procedures. The third narrative strand I investigate here joins intrinsic and instrumental accounts of democracy in developing an approach to justice (Sen, 2009; Shapiro, 1996; Shapiro, 1999; Young, 1990). I turn now to each of these perspectives.

Those advancing the instrumental view of democracy contend that justice and democracy may be reconciled by (re)designing institutions and procedures (Dowding, Goodin, & Pateman, 2004; van Parijs, 1996). Van Parijs (1996) has argued that democracy and justice may only be reconciled through carefully considering various possibilities and selecting a course that permits the best chance of, “rendering our world a little more just.” (p.114) His conception of democracy is purely procedural: it combines majority rule, universal suffrage and free voting, in which all voices are heard (p.102). His construct is consonant with Schumpeter and Hayek’s views of democracy. Van Parijs sees democracy not as an end in itself, but as an instrument in efforts to attain an ideal of justice (p.111). Only this form of democracy will lead, in his view, to justice, which he conceives as maximizing the material conditions of the least advantaged members of society (p.102). When justice and democracy clash van Parijs (1996) argues for adhering to justice and sacrificing democracy, since the latter is only an instrument, “from which it is legitimate to deviate *if* the pursuit of the ideal requires it” (p.110, italics in the original).

Dowding (2004) has contended that arguments for just institutions and for democratic ones may be justified through the same logic. Defending both procedural democracy and

procedural justice, he makes room for challenging both if their outcomes differ sharply and continuously from expectations (p.33), although he does not specify how. Dowding concludes that arguments for changing the institutions promoting democratic outcomes and just ones proceed from, “the unjust consequences that follow from the institutions we have” (p.39). This, however, does not make Dowding’s argument strictly instrumental. Rather, he defends both procedural democracy and procedural justice, in which democracy is viewed as instrumental in promoting just outcomes, but he urges changes in both democratic and justice-related institutions since each may create unjust outcomes. When injustice can rightly be attributed to unfair democratic processes, Dowding argues it makes sense to challenge those processes.

Dowding’s argument concerning the shared bases of advocacy for just and democratic institutions is helpful when one considers its broader implications for public policy-making. If a particular instance of injustice calls for policy action, it is important to design that effort to strengthen social justice and democratic participation, in so far as possible. A good example of this is assurance of a basic income in society, which is often presented as a matter of distributive justice. However, Pateman has argued that ensuring basic income can be viewed as a democratic imperative as well (cited in Dowding, Goodin & Pateman, 2004, p.11). Indeed, if their incomes are insufficient to allow for the provision of the essential needs of the poor and disabled, these groups, including their families, will spend more time and effort fulfilling those necessities, leaving less, or even no space and resources available for democratic participation.

Intrinsic accounts claim the justness of democracy on the grounds of that system of political organization and not extrinsic criteria. Dahl (1991), for example, has argued that democracy cannot violate justice and still be a democracy, and while unjust outcomes happen, they are mistakes, for which a corrective mechanism can be created to avoid similar errors in the future. Similarly, Cristiano (2004) has suggested that the democratic process is intrinsically fair, and that justice is, “the principle of the public realization of equal advancement of interests” (p.269). The big questions related to establishing justice for Cristiano (2008) are, “whether the rules were arrived at in a reasonably just way and whether the rules themselves are at least within some range of tolerability” (p.55). On the grounds of the principle of publicity, when each person is not only treated justly, but also is able to see that this is so, he argues that only democratic decision-making can serve as a reasonably apt mechanism to conceive of the steps required to attain that result. However, Arneson (2004) has denied that publicity is an intrinsic component of justice, arguing that if autocracy is able to deliver just results, it can conform to the publicity imperative. On this basis, Arneson (2004) has contended that democracy is not intrinsically just (pp.25-26).

Valentini (2010) has also suggested that democratically devised rules may fail to satisfy the demands of justice (p.3). She contends that democracy is intrinsically just only under specific conditions, which she stipulates to be deep reasonable disagreement. When citizens reasonably disagree concerning both the substance and processes of justice, Valentini suggests that justice can be attained via deliberation and majority rule. She defines justice as equal respect and views democracy as a set of decision-making processes in which all affected have an equal say in determining governing rules. However, it should be borne in mind that having an equal say does not mean that some individuals will not voluntarily refrain

from participation. It may imply instead simply that there is no involuntary lack of participation, a situation that could undermine both justice and democracy. Moreover, when citizens deeply disagree about justice (substance and processes), Valentini's argument quickly proves insufficient.

Finally, there is scholarship that conceives of the relationship between democracy and justice in both intrinsic and instrumental terms. Shapiro (1999), for example, has argued that democracy is a "subordinate foundational good, designed to shape the power dimensions of collective activities" (p.18). Drawing on empirical examples, Shapiro contends that people tend to "blame social injustice on democracy's absence," thus assuming that the form of governance employed represents an important means to achieve more just social relations (Ibid). Such popular expectations concerning the relationship between democracy and justice do not mean that every form of democracy promotes justice. Indeed, Shapiro (1999) establishes a "dual aspiration" for his framework of democratic justice: "to articulate a conception of justice that accords a central place to democratizing social life, and a view of democracy that can be justice-promoting rather than justice-undermining" (p.21). He presumes a view of society in which "no domain of human interaction is beyond politics" (p.6) and a wide-ranging conception of justice, embracing "every aspect of human interaction" (p.11). While in this view justice is accorded a privileged place relative to democracy, that form of governance nonetheless has intrinsic value. Shapiro focuses on power relations and social hierarchy and is concerned with mechanisms of participation and opposition beyond electoral process. This conception of democratic justice aims at improving existing institutions and practices through critical scrutiny (Shapiro, 1999, p.233).

Young (1990), meanwhile, has suggested that citizens voice their interests instrumentally via participation, since justice requires popular engagement in public discussion. Intrinsically, democracy is a, “condition for a public’s arriving at decisions whose substance and implications best promote substantively just outcomes, including distributive justice” (p.92). Thus, a policy can claim to be just if it was arrived at through deliberation, which encompassed the free expression of all points of view (Young, 1990, pp. 92-93). Young objects to the idea that grassroots participation in decision-making may lead to unjust outcomes because it helps introduce standards of justice into decision-making as well as promotes social knowledge and perspectives fruitful for policy deliberations (p.93). She claims that constitutional democracy and extensive redistribution of wealth and restructuring of control over resources are necessary to secure the complex relation between democracy and justice she proposes (p.94). Moreover, Young (1990) contends that with economic equalization citizens have greater opportunity to participate in public discussion and decisions that affect them. However, even with the achievement of economic equality, otherwise formally equal procedures may allow bigger and more resourceful groups to oppress other entities. The only possibility of avoiding this, Young (1990) suggests is, “if oppressed groups are able to express their interests and experience in the public on an equal basis with other groups” (p.95). This criterion is, of course, a very difficult one to achieve.

For his part, Amartya Sen (2009) has argued for a theory of justice that, “is not confined to the choice of institutions, nor to the identification of ideal social arrangements,” but also linked “to the lives that people can actually live” (p.18). Sen’s (2009) vision of democracy includes, beyond electoral process, “political participation, dialogue and public interaction” (p.326). He has defended his view on both intrinsic and instrumental grounds,

arguing that the practice of democracy has inherent value for human life through the practice of political and social participation, the lack of which constitutes a major deprivation (Sen, 1999, p.10). For Sen, democracy is also instrumental in advancing justice. He (2009) sees public reasoning as constitutive of democracy and at the same time as an aid in assessing the demands of justice, thus creating a connection between the two (p.326). He advances an accomplishment-based understanding of justice and proposes a capability approach rather than resource-centered focus on wealth as a basis for evaluation of justice. Sen's capability approach suggests considering the opportunities people actually have (Sen, 2009, p.253) and judging individual advantage based on, "a person's capability to do things he or she has reason to value," focusing on "the freedom that a person actually has to do this or be that" (Sen, 2009, p.231). Sen (2009) focused on the expansion of human capabilities for all in society, without proposing any specific formula for policy decisions or offering a way for dealing with potential conflicts among different considerations (pp.232-233).

To conclude, I find the argument that democracy and justice are linked both intrinsically and instrumentally more compelling than purely instrumental or intrinsic accounts of the relationship between democracy and justice. Instrumentalists mostly conceive of democracy as fair processes, without robust citizen engagement and without economic equality. In my view, a governance structure that lacks these attributes undermines both democracy and justice. Charles Taylor (1992) has argued instrumental reason represents a central malaise of modernity and further enlarging its social scope may lead to a situation in which the enshrinement of efficiency, or its corollary cost-benefit analysis, undermines democracy. In the context of Latin America, establishing minimal democracy, at times even in a hybrid combination with authoritarianism, has occurred on several occasions, yielding

elitist, hierarchical and patrimonial forms of governance (Hillman, Peeler & Silva, 2002, p.2). This makes me question the explanatory power of the purely instrumental and intrinsic accounts discussed above. With significant economic, social and political inequalities, Latin American democracies have hardly been intrinsically just. Also, by allowing for a trade-off of democracy for justice, instrumentalists make accounts of democracy vulnerable to autocratic elements, a real threat in Latin America. As I contend in Chapter 4, the relatively recent military dictatorship in Brazil's history stalled the development of democracy in the nation. Levine and Molina (2011) have evaluated the quality of democracy of several Latin American nations and have ranked Brazil slightly below the average in the region due to the autocratic elements still present in Brazilian political culture following more than two decades of democratization.

### **Democracy and Human Rights**

Democracy and human rights have increasingly been linked by human rights agencies and activists as well as by many Western governments as part of their foreign policies (Beetham, 1999, p.89). As Beetham has observed, an adequate understanding of the relationship of human rights and democracy depends very much on the way one defines and justifies democracy and human rights (Ibid). This discussion relates to my argument above concerning the relationship between justice and democracy, since human rights are related to both concepts in the accounts below. Together with the previous section, this one on the connections between democracy and human rights contributes to understanding how promoting disability rights influences democratic development and efforts to advance justice in Brazil. Considered in a somewhat simplified way, the debates concerning democracy and

human rights can be grouped as symbiotic and non-symbiotic accounts. The first listed unites claims that promoting democracy also enhances human rights, or that encouraging human rights also fosters democracy. The latter account suggests that democracy does not necessarily promote human rights protection.

Many scholars assume human rights and democracy are symbiotic. Goodhart (2005), for example, has developed an account of democracy as human rights (DHR), in which he laid out the normative and institutional requirements of freedom and equality as promoting, “universal emancipation through securing human rights for all” (p.135). Goodhart bundled fundamental human rights into four groups: those linked to liberty and security, fairness, ensuring an adequate standard of living and civil and political rights. He pushed beyond negative rights in his framework, but not so far as to offer a substantive vision of the good life. He maintained that DHR does not pretend to “exhaust popular politics,” but rather “specifies the democratic core of politics,” by providing a framework to address political problems (pp.162-163). As I understand it, this theorist views democracy in processual terms by focusing on the mechanisms by which rights are guaranteed.

Like Goodhart, Gould (2004) has placed human rights at the core of democracy, but she has gone further to offer a substantive account of democracy as well. Gould (2004) views democracy as based, “on reciprocal and empathetic personal relations” (p.2), arguing for a conception of human rights in relational terms: “individuals bear these rights only in relation to other individuals and to social institutions” (p.37). She contends the relation between democracy and human rights is dialectical: while democratic participation provides an avenue for protecting human rights, the protection of such rights in itself represents a condition

necessary to secure extensive democratic participation (p.4). Distinguishing between formal (or procedural) and substantive democracy, she argues for a vigorous conception of democracy that “is itself one of the human rights” (p.196), in which human rights pose a “legitimate constraint [...] on democratic decision-making” in social, economic and political contexts (p.4). Her conception of substantive democracy is based on the self-development of participants in which they, “reciprocally recognize each other’s freedom and equality in the process of making collective decisions” (p.39).

Similar to Gould, Beetham (1997) has argued human rights constitute an intrinsic component of democracy and should be defined both in terms of governing institutions and basic civil and political rights. Moreover, he (1999) has outlined three classes of rights—civil and political, economic and social and cultural—that each relate to democracy in different ways (p.114). In his view, while civil and political rights comprise an “integral part of democracy,” economic and social rights stand in “mutual dependency” with democracy (Ibid). That is, according to Beetham, democracy requires economic and social rights as much as it does civil and political ones, but in a less direct way. As he (1997) has contended, “economic and social rights have an importance not only for equal citizenship, but also for securing democracy as a whole” (p.356). Finally, in this view cultural rights require the analyst to re-conceptualize democracy and its processes, if equal citizenship is to be realized in the context of multicultural societies (Beetham, 1999, p.114).

Similarly, Zucker (2001) has offered a substantive vision of democracy, which entails economic rights along with political rights, cautioning that otherwise, “the standard list of democratic rights is incomplete” (p.277). Examining young democracies, Arat (1991) has

observed that in that context, civil and political rights cannot be guaranteed when socioeconomic rights are undermined (p.4). To buttress her claim she has argued, “the stability of political democracy (liberal democracy) depends on the extent of balance between the two groups of human rights” (Ibid). When this equilibrium is violated and socioeconomic rights are ignored, young democracies risk sliding into authoritarianism (Arat, 1991, p.9).

Several authors have suggested that establishing goals to promote human rights also furthers democracy and development. Donnelly (1999), for example, has contended that analysts should focus on assuring the creation of rights-protective regimes, which will promote both democracy and prosperity (p.631). Frank (1988) has argued meanwhile that the right to self-determination embraced in the Universal Declaration of Human Rights—UDHR—de facto constitutes a human right to democracy (cited in Evans, 2001, p.631), although the Declaration does not formally specify a form of government. Moreover, the precise link between self-determination and a universal right to democracy remains unclear (Freeman, 2000, p.34), since realizing the criterion, "must permit a people to decide its own political system and form of government" (Evans, 2001, p.632).

A number of scholars have cautioned that democracy does not necessarily entail human rights protection (Carothers, 1994; Donnelly, 1999; Evans, 2001; Freeman, 2000; Köchler, 1990; Mesquita, Downs & Smith, 2005; Waldron, 1993). Mesquita, Downs and Smith (2005) have analyzed the aspects of democracy most important in addressing and mitigating human rights violations and found that, “simple increases in a state’s level of democratization do not lead to commensurate reductions in human rights violations” (p.456). They have argued that a, “structural change is necessary for behavior to change, but behavior

does not change until enough structures are in place to make it compelling for political leaders to restrain themselves and to respect the rights of their subjects” (p.455). They framed this imperative as a critical threshold on specific dimensions of democracy that ensure accountability and translating institutional changes into behavior (p.443). These scholars concluded that competitive political participation and high levels of democratic development and accountability are among the most important factors shaping states’ human rights records.

Many existing democracies have sought to protect human rights by providing for them in a written constitution. Arguing from a rights-based approach, Waldron (1993) has critiqued attempts to provide for constitutional protection of rights, suggesting such efforts, “shift decisions about conceptions and revision of basic rights from the legislature to the courtroom, from people and their admittedly imperfect representative institutions to a handful of men and women” (p.20). Waldron has argued judicial protection of rights is ultimately undemocratic, and he may have a point when he criticizes removing human rights issues from public deliberation where there are presumably both horizontal and vertical accountability mechanisms in place. However, constitutional protection of basic rights helps to ensure that those claims will not change on a majority whim and thereby provides a measure of stability. In Chapter 8, I refer to one such example offered by Young (1997), in which Oregon state officials decided not to subsidize health services for disabled people in the same way as those for nondisabled people, after conducting a phone survey of nondisabled residents. Moreover, in democracies, the process of constitution making itself entails a consensual procedure of institutionalizing basic rights. Gould (2004) has claimed that constitutional rights are recognized as rights even before being institutionalized, which eventually consensually makes them constitutional (p.40).

The authors treated here have raised many complex and critical arguments regarding human rights and democracy. Feminist legal theory scholars have added another level of intricacy to this mix of perspectives. Baynes (2000), for example, has expressed ambivalence about the employment of rights-based arguments as a means to achieve gender equality (p. 465). For her part, Minow (cited in Baynes, 2000) has expressed concern that factoring another person's difference into distributing goods risks restating the significance of that difference and potentially reinforcing its stigma and stereotyping consequences. On the other hand, not acknowledging differences may reinforce both the distinctions and their negative implications (Baynes, 2000, p.465). Thus, the effects of laws will not be neutral regardless of whether they take difference explicitly into account or ignore it.

The point for these scholars is not to reject rights discourse, but, as Baynes (2000) has observed, to acknowledge the need to reassess their impact on the concrete experiences of those subjected to inequality (p.465). If legal institutionalization of the rights of those with impairments is a crucial means to allow them to attain their dignity, many laws and policies should be changed. One of my interviewees, a young physically impaired woman told me, for example, that she was receiving 64 adult diapers per month because she needed them. However, this stock was sufficient only for half the stipulated period, which meant that she had to manage her situation for the remainder of each month or buy diapers herself from the minimal salary she earned (about 300 USD per month). As a practical matter, it is worth asking what would occur if she were to go back to her studies and leave home on a daily basis. How would state assistance with 64 diapers relate to her life experience? While the government guarantees her health-related right in principle, in practice, it clearly does not meet her everyday needs in a fashion that allows the realization of that claim.

## **Social Justice and Social Policy**

Different theories of social justice address the multiple dimensions of inequality in disparate ways. This study seeks to consider the implications of social justice theories for policy problems. That is, it is important to consider the role and place of justice in people's lives and how prominent theories of justice help to understand rights, equality and wealth distribution. Unfortunately, there is a gap between theories of social justice and policy applications (Piachaud, 2008; Wolff, 2008). This study seeks to address that disjunction, at least in terms of justice, for disabled individuals in Brazil. Theories of social justice employ a number of concepts, including inequality, rights and citizenship that can be used in social policy design and implementation. However, different scholars offer different definitions of these concepts and what kinds and degrees of inequality or rights violations are unacceptable (Craig, Burchardt, & Gordon, 2008, p.6). The understandings of justice reviewed below will serve as broad categories by which I will evaluate the constructs that either my interviewees or my discourse analysis yield. Thereafter, I will discuss the connections of various theoretical approaches to social justice to Brazil's social policy debate.

First, it is important to note that while for analytic purposes different dimensions of justice can be separated, they are not so compartmentalized in the lives of individuals. As Craig, Burchardt, and Gordon (2008) have observed, these dimensions, "are not just interrelated at the individual level, they may be inseparable" (p.12). An intellectually impaired person does not disconnect his or her experience of injustice when facing difficulties in obtaining basic income assistance payments, when he or she has no guaranteed access to healthcare, when rejected or even mocked in the community or when the individual has

difficulty securing employment or continuing education. Thus, acknowledging this interdependence does not allow for a reductionist approach to theories of justice as well as to social policy metrics, since no single indicator can sufficiently capture the relevant aspects of life (Ibid).

Second, to understand better the implications of key debates among social justice theorists for their policy implications, I survey the main points of discussion in relevant literature. Wolff (2008) is helpful in broadly summarizing those essentials. While some scholars propose that social justice requires equality (e.g., Nussbaum, 2006; Rawls, 2001; Sen, 2009; Young, 2008), others have contended sufficiency is a more relevant aspiration, suggesting that what matters is whether people have adequate economic assets to flourish (Frankfurt, 1987). Yet others argue for assigning priority to the worst-off when goods and services linked to justice claims are distributed (Parfit, 1998, cited in Wolff, 2008). Piachaud (2008) has contributed to this discussion by pointing out that the social justice debate concerning equality is split between advocates of equality of opportunity (variously understood) and equality of outcomes (p.33). Egalitarian theorists debate the issue of ‘equality of what?’ As a group, these analysts contest the relevance and utility of such metrics of justice as income and wealth, resources, opportunities and capabilities to function (Wolff, 2008, p.22-24).

Several scholars have framed equality in terms of social relations rather than fair procedures (e.g., Lister, 2008; Young, 1990; Young, 2008). Young (1990), for example, has argued equality must be understood as, “full participation and inclusion of everyone in a society’s major institutions, and the socially supported substantive opportunity for all to

develop and exercise their capacities and realize their choices” (p.173). She has been quite critical of contemporary liberal societies that have adopted a liberal paradigm of equality in which that term is viewed as sameness, ignoring differences among groups in how they are treated by public policy. Young (2008) cautions that such a difference-blind approach is likely to reinforce structural group differences and inequality due to existing practices, hegemonic norms, effects of past policies and stereotyping assumptions (pp.80-81). One study of the implications of employing cost-effectiveness as a strategy by which to evaluate the health benefits to be provided individuals with impairments provides a good example of Young’s point. Bognar (2011) found that the use of cost-effectiveness analysis, the standard analytical tool in evaluating health benefits and programs, lead to unfair discrimination against individuals with impairments in liberal societies.

Proponents of intrinsic justice focus mainly on political and social institutions and miss cultural factors for a more comprehensive explanation of the relationship of democracy to justice. Thus, Young (2008) has observed that in order to, “remove unjust inequality it is necessary explicitly to recognize group difference and either compensate for disadvantage, revalue some attributes, positions or actions or take special steps to meet needs and empower members of disadvantaged groups” (p.81). Similarly, Lister (2008) has argued that social justice should be a combination of “distributive and recognition perspectives” (p.105), referencing the struggle of disabled individuals for both “material and cultural forms of justice” (p.110). These claims are important for not reducing social policy to the content of redistribution in the case of the disabled, but also in recognizing the equal moral worth of those targeted and the need for respect and non-discrimination of them together with guaranteeing social security benefits.

Income redistribution for greater equality is justified or rejected in justice theories on different grounds. For utilitarianism, for example, income redistribution based on criteria of necessity may be justified as long as the benefits to the needy provide more utility to those assisted than the loss of utility suffered by those on whom taxes were levied (Sposati, 2004, p.16). Sposati condemns utilitarian thinking on the grounds that it seems to be justified even if it causes extreme misery and deprivation to those already disadvantaged, which contradicts the idea of social justice. Stein (2006), on the other hand, has suggested that utilitarianism can be successfully used to argue for distributive justice for the disabled, assuming that resources are in fact distributed to those individuals who can most benefit from them rather than to those who are worse-off. He has argued that, “utilitarianism will not approve of aid to the disabled that would benefit them only slightly and would divert resources from alternative uses that could provide people with greater benefits” (p.4). However, Stein does not elaborate on who decides “greater benefit” and how it is measured. If two young physically impaired people need a wheelchair—one to attend college and another to work—is the benefit from higher education greater than the benefit from employment? Are these benefits evaluated on a short- or long-term basis? Moreover, this approach would condemn individuals with severe impairments to never having anything allocated to them because many physicians and educators do not acknowledge even the slight benefit they can gain from such interventions. More broadly, this problem illustrates the difficulty that utilitarianism as a construct has in dealing with human diversity and broader conditions that create and sustain social inequalities and the implications of those differences for society.

John Rawls wrote his *Theory of Justice* (1971) as an objection to utilitarianism. He stressed the importance of social protection institutions as a facet of social justice and argued

that in a democratic society each person should have an equal right to basic liberty, compatible with a similar freedom for all. Rawls also posited that the justness of society should be judged by how well it treats its worst-off citizens. By proposing two principles (equal basic liberties and the difference principle) on which people would agree behind a posited veil of ignorance (Rawls, 2001, pp.42-43), Rawls built an argument against arbitrary factors resulting in different life opportunity sets for individuals. He called for neutralizing the effects of natural endowments and social contingencies and suggested the veil of ignorance for that purpose. Rawls contended that people would be motivated if they see the principles of justice as a product of their choice. In discussing what motivates individuals to choose behind the veil of ignorance—goodness or rightness—Rawls originally argued that rightness prevails over goodness, since autonomous agents choose the principles of justice, rather than goodness over rightness since the chosen ends do not have intrinsic value for the agents (Rawls, 1971, p.452). However, in *Justice as Fairness: A Restatement*, Rawls contended that while citizens do not affirm the same comprehensive doctrine, they do share the same political aspiration, “the end of supporting just institutions and giving one another justice accordingly” (Rawls, 2001, p.199).

Rawls’ great concern in these major works was the stability of society, and thus of justice, and he argued accordingly that principles and arrangements undertaken on the basis of justice as fairness represent a “reasonably stable moral conception” (Rawls, 1971, p.436). In striving to devise clear and sharp premises, the Harvard-based philosopher aimed foremost at ensuring the stability of a social system, in which just principles become part of everyday practice. For Rawls, stability was secured by just institutions promoting appropriate and sufficient motivation, “The kind of stability required of justice as fairness is based on its being

a liberal political view, one that aims to be acceptable to citizens as reasonable and rational, as well as free and equal” (Rawls, 2001, p.185).

Libertarianism claims the absolute primacy of individual liberty. This perspective has generally implied strong protection of private property and at least an implicit belief in market supremacy and hence a desire to limit and circumscribe the State’s power and any concern it might evidence regarding social justice (Nozick, 1974; Sposati, 2004). In this view, a just society is one in which any form of social protection by the state is completely rejected in the name of individual liberty and respect for private property rights. Nozick viewed redistribution of wealth as coercion and argued such action violated the principle of self-possession: “There is no justified sacrifice of some of us for others” (Nozick, 1974, p.33). Libertarians have justified a minimal state, limited to protection against theft, fraud, force and enforcement of contracts, and have argued against any “paternalistic” legislation (Nozick, 1974, p.ix) such as, for example, social benefit payments or employment or educational supports for the disabled. Among other implications, this argument allows the distribution of wealth in a society to be based on factors such as accidents of birth, impairment-causing accidents, etc.

One of the principal critiques of Rawls offered by Sen (2004) and Nussbaum (2006) is his interest in primary social goods and that he did not consider the differences in the natural goods with which individuals are endowed by birth. That is, some critics have contended that he neglected individual capabilities that could transform personal capacities into real liberty or realizable wellbeing (Sposati, 2004, p.20). As Sen has noted, “They [primary goods] are assets and resources that are “external” to the person; they do not capture what the person can

do with the assets and resources he or she has” (Sen, 2004, p.6). Sen has suggested that income and wealth are inadequate indices of the security of people with disabilities (Nussbaum, 2006, p.164). Sen and Nussbaum have sought to fill this gap by developing different versions of a capability approach. Sen described his view as one, “concerned with evaluating it [person’s advantage] in terms of his or her actual ability to achieve various valuable functionings as a part of living” (Nussbaum & Sen, 1993, p.30). According to Sen, disability makes it harder not only to earn income, but also to convert it into the freedom to live well, which he dubbed as ‘income handicap’ and ‘conversion handicap’ (Sen, 2004, p.4). Using the example of the United Kingdom, Sen compared people below the poverty line with and without a family member with disability, demonstrating a 20 percent income disadvantage gap for families with a disabled member. He attributed one-quarter of that disparity to the income and three-quarters to the conversion handicaps (Ibid).

Nussbaum introduced her version of the capabilities approach by seeking to determine what basic principles and measures thereof would fulfill a life of human dignity. She insisted on the same list for all citizens and posited the notion of a threshold level of each of the capabilities, “beneath which a decently dignified life for citizens is not available” (Nussbaum, 2006, p.179). She framed these fundamental principles as, “central human entitlements in terms of which basic social justice is defined” (Nussbaum, 2006, p.166). Nussbaum distinguished situations when capability or functioning was an appropriate goal for public policy. For example, such efforts are apt for children as well as for people with severe cognitive impairments (Nussbaum, 2006, pp.172-73). Indeed, more deeply, “in the area of self-respect and dignity itself [...] actual functioning is the appropriate aim for public policy” (Nussbaum, 2006, p.172). For people with severe cognitive impairments, based on the idea of

human dignity, Nussbaum advocated for the same single list of capabilities and the threshold as those without handicaps, but emphasized broader items rather than their more specific component parts. For example, for the profoundly impaired she emphasized control of the material environment instead of employment, alternative ways of securing or exercising political membership and the possibility of some political activity rather than voting, if the person cannot hold a job or vote (Nussbaum, 2006, p.194).

Several scholars have discussed the practical importance of social justice debates for policy. Wolff (2008), for example, has argued that for overall well-being, it is less crucial that public policy pursue equality or high sufficiency, because whichever aspiration is adopted, the immediate aim of government action will be to improve the lives of those worst-off in society, prioritizing their needs in both the short and medium-term (p.27). Drawing on Rawls and Sen, Piachaud (2008) has suggested equality and equity should be viewed as distinctive with the latter viewed as the appropriate goal for social policy. He has maintained that not all inequalities are suspect, arguing that for social policy, “efforts to alter opportunities and capabilities may be more equitable than efforts to alter outcomes” (p.45), and by doing so, social policy is more likely to reduce income inequality (p.46).

Burchardt (2008) has offered a compelling case study that applied the capability approach to public policy. Seeking to develop a framework for assessing inequality across a range of social groups, she and her colleagues based their work on both international human rights treaties and deliberative consultations to recognize the diversity of people’s views and goals concerning multiple aspects of equality. Notably, participants included a number of items from Nussbaum’s list in their deliberative consultations, including emotions, affiliation

and practical reason (p.215). Many policy practitioners fear the capabilities approach is “unworkable in practice” (p.225) because of the “complexity in measurement and high informational demands” it entails (p.224), but Burchardt powerfully contends that governments should, “adopt a genuinely multidimensional interpretation of equality” (p.225).

### **Disability Theory and Disability Rights**

Disability as a subject of ongoing investigation has occasioned the development of a number of conceptual frameworks. Bodies and their variations can be engaged through single, multi- and interdisciplinary approaches, biologically or medically, phenomenologically, as discursive constructions, social constructions and so on. While Western scholars have studied disability for many decades, analysts have largely ignored it as a human rights issue, as Lynch (2012) has noted. This section first surveys key distinctions and debates among disability theorists and then discusses the concern as a human rights issue.

Many disability scholars and practitioners locate the field’s theoretical diversity along a spectrum bounded by two polarities: the ‘individual model’ and the ‘social model’ (see, for example, Barnes, Shakespeare & Mercer, 1999; Harris & Enfield, 2003; Shakespeare, 1998). Disability studies scholars have also suggested distinguishing inquiry into disability between approaches that emphasize socio-political-cultural factors and those that stress medical strategies (Linton 1998b; Lynch, 2012; Shakespeare, 1998; Thomas, 2007). Yet another group of theorists has offered more nuanced positions, challenging the social constructivist and social model approaches to disability studies as limited and insufficient (Corker & French, 1999; Schillmeier, 2010; Scully, 2008; Siebers, 2001; Siebers, 2008). I detail the claims and

assumptions of each framework below. These basic concepts are helpful when discussing disability in terms of human rights. Moreover, this foundation will help in understanding where Brazilian society now stands in how it treats people with impairments.

The medicalization<sup>2</sup> of disability that occurred in the 1970s, established an ‘individual’ model that became, “the professional, policy and lay orthodoxy through the twentieth century” (Barnes, Shakespeare & Mercer, 1999, p. 20). In the individual model, the lives of people with impairments are dominated by a vast army of professionals, i.e., physical therapists, specialized physicians, psychologists, etc., who are the presumed holders of a “solution.” Under this approach, a person with impairments is compared against a normative ideal of able-bodiedness (Lynch, 2012) and is consistently called upon to, “make every effort to make the best of their circumstances by individual adjustment and coping strategies” (Barnes, Shakespeare & Mercer, 1999, p.26). Medicalization was followed by the implementation of medical social control, in which doctors became information providers, gatekeepers, institutional agents and technicians, and offered aid via medical technological means, especially by means of drugs, surgery and genetic or other types of screening (Conrad, 1992, p.216).

Oxfam and Action Aid have offered a variation of the distinct individual and social conceptual frameworks of disability in their training manual for Development and Humanitarian Organizations on Disability and Human rights (Harris & Enfield, 2003, p.172). The models outlined there—charity, biomedical and social—are based on the central question of determining who bears responsibility for the supposed “problem” and concerns associated with it. Proponents of the charity perspective view disabled people as victims of their

impairment, needing special services and institutions, etc., because they are different. Sometimes disabled people themselves adopt this perspective, in which case they usually feel “unable” and evidence low self-esteem. Meanwhile, as noted above, the biomedical model considers people with impairments as individuals with physical (and other) problems that need to be treated and presumably, “fixed.” By locating the impairment problem with the person, both the charity and biomedical models stand at the ‘individual model’ end of the theoretical spectrum, viewing such individuals either as victims of their impairments or having physical problems that must be healed. Although many physicians realize that some conditions cannot be “cured,” by nonetheless choosing to “normalize” people with impairments, societal norms often echo the “medicalization of disability,” thereby endorsing dealing with the “problem” by tasking the medical establishment, to “treat” the person rather than revisit social processes (Linton, 1998a, p.11). Meanwhile, acknowledged or not, those processes contribute to the social construction of disability and impairment.

Both of these social constructions (charity and biomedical models) can disempower impaired people and prevent them from exercising their rights. The aim of the medical approach is to intervene to assist impaired people to attain a “normal” state, which implies they are in some way abnormal. In this view, the disability is limited to the individual in question and the impaired person must be changed, rather than changing society or the surrounding environment to accommodate their condition (by providing, for example, ramps, automatic doors, elevators, etc.).

Finally and in contradistinction, the social model regards disability to be a result of the way society is organized. This perspective suggests that because social orders are not just, and

people with impairments face attitudinal, environmental and institutional discrimination. These barriers make it difficult for these individuals to take control of their lives and imply the need for laws that address them. However, as pointed out earlier, such statutes by themselves may potentially reinforce existing social stigma and discrimination rather than diminish them. As suggested above, factors such as the dominant beliefs evident in political culture, among others, should be considered when designing efforts to reduce discrimination and to promote equal citizenship.

Linton has suggested a rationale for a liberal arts-based inquiry into disability, which she has described as Disability Studies as distinct from traditional interventionist approaches that she has labeled, Not Disability Studies (Linton, 1998b). As Linton has observed: “Special education, rehabilitation and other disability-related fields were and remain more clearly a reaction to social need than fields determined by a set of principles and ideas” (Linton, 1998b, p.528). Thus, she has stressed the importance of addressing impairment and disability as two separate realms of discourse (Linton, 1998b, p.527). In a similar vein, Thomas (2007) has provided an informative and critical account of the disciplinary divide between disability studies and medical sociology, advocating for a ‘sociology of disability’ to address that separation. She argues that while sociologists in disability studies have been concerned with social oppression, medical sociologists have theorized chronic illness and disability from the standpoint of social deviance.

The distinction between impairment and disability has constituted one of the major dilemmas in disability theory (Corker & French, 1999; Schillmeier, 2010). Some scholars have suggested different cross-disciplinary relationships between the non-social

characteristics of the disabled (disabled body) and their social ones (moral imagination, social representations, political struggle, etc.). Siebers (2001), concerned with representations of the disabled body in scholarship, has warned of the limits of a social constructionist approach. In this analyst's view, with the linguistic turn in theory development, language became the agent and never the object of representing disability, thus excluding embodiment (Siebers, 2001, pp.738-39; Siebers, 2008, p.2). Put differently, disability is not always a product of a mismatch between, "social design and some human bodies," even though such is often the case (Siebers, 2001, p.740).

Wolff (2008) has offered an argument that clarifies Siebers' point. He has suggested organizing the factors that affect people's life opportunities into three categories, which helps to imagine a range of possible strategies to address disadvantage for disabled individuals and reveals many sources of social hardship and oppression:

- Internal resources (strengths and skills);
- External resources (wealth, income, family support); and
- Social and material environment (laws, customs, culture) (p.25).

Corker and French have offered a critical insight into the social model of disability, cautioning that because of the epistemological dualism established between impairment and disability, the model, "produces and embodies distinctions of value and power" (Corker & French, 1999, p.2). Drawing on earlier insights offered by Oliver (1999), Corker and French distinguish between disability studies and the 'social model' of disability, claiming the 'social model' does not fully embrace contemporary disability studies, while the latter is founded on the social model theory (Corker & French, 1999, p.7). It happens because the social model of

disability dichotomizes disability and impairment: the distinction between socially created disability and impairment, which is a physical attribute (Corker & French, 1999, p.2). This division breaks the conceptual link between disability oppression and impairment, as if they were not related (Idem).

Stein (2007) has pointed up another limitation of the social model's influence on legal instruments: "because it exclusively concentrates on first-generation rights [civil and political], the social model is prevented from invoking a full range of second-generation rights [economic, social and cultural]" (p.91). Stein has insisted on the importance of second-generation rights, as they entitle the disabled to equal opportunities because they are humans, thereby allowing for individual differences (p.92). Earlier, I drew on Beetham (1999) who has pressed Stein's argument further, arguing that social and economic rights are important for securing civil and political rights.

Lang (2009) has referred to a group of 'second generation' disability theorists who have questioned the social model on the grounds of its, "universal and homogeneous experience of discrimination and oppression" (p.278). These scholars assert the existence of a 'social hierarchy of impairment' in which, "some impairment groups are deemed to have more political credibility than others" (Ibid). This argument, Lang notes, poses serious challenges to traditional political strategies that the disability rights movement has deployed to secure rights for the impaired and to promote a rights-based approach to disability (Ibid). However, as I show in the last section of this chapter, a combination of approaches can be used to address different levels of disadvantage within the larger group of individuals with impairments.

Existing scholarship on disability in Brazil is mainly concentrated on the applied side of education, employment, healthcare and law (linked to the accessibility of public spaces and websites, public transportation, sign language interpreters in universities, TV and other public institutions, etc.). Only a limited number of Brazilian works discuss disability rights,<sup>3</sup> discourses<sup>4</sup> and citizenship. The kind of theoretical diversity concerning disability that exists in United States and United Kingdom scholarship has not yet developed in Brazil nor, indeed, has the field of disability studies yet formed as a discrete area of inquiry in the country.

Scholars and human rights activists in Brazil and other countries have not deeply explored disability as a human rights issue in general. Lynch (2012) has recently observed that Sen's capabilities approach may benefit disability scholarship and complement a social constructionist approach to the field by treating human capabilities as universal and people as having the right and therefore opportunities to develop their capabilities. For his part, Stein (2007) has developed a "disability human rights paradigm" by combining a social model of disability, Nussbaum's version of the capabilities approach and a basic human right to development. Because this social model is concerned with formal justice, neglecting economic, social and cultural rights, Stein combined it with Nussbaum's framework, which requires that every person be treated as an end and provided with the means through which to develop their potential. Nussbaum's capabilities approach, "improves the human rights framework by providing content to its otherwise abstract aspirations of protecting autonomy, ensuring dignity, and developing personal capacity" (Stein, 2007, p.101). However, Stein is critical of Nussbaum's framework because it does not ensure the full dignity of certain individuals with severe impairments who function at levels below her posited ten central capabilities (Stein, 2007, p.102). Thus, he proposes focusing on developing each person's

talents in ways that, “can benefit her and society” (p.106), instead of Nussbaum’s capabilities and functionings. However, Stein’s approach raises questions of its own. First, if individuals of all talents are equally supported in his framework, what conditions signal success? For example, if someone possesses two or more talents, should society allocate resources to develop all of her capacities? Or, if an individual received resources to develop her capabilities, but will not employ them in an occupation/productive activity, should that allocation still be considered a benefit to society?

Mégret (2008) has critically evaluated the UNCRPD to distill the lessons that the document has to teach about human rights more generally. Although a more detailed analysis of the significance of the Convention and its content and implementation challenges will be provided in Chapter 5, I want here to draw on his conclusion that the treaty did not create what he calls “a ‘ghetto’ of ‘disability rights,’” but instead it reformulated, expanded and innovated on basic human rights concepts for this population (Mégret, 2008, p.516). Mégret calls them “disability human rights”—specific to the experience of disability—yet “rooted in the universality of rights” (Ibid).

Although Iris Marion Young did not write specifically on disability issues, her insights into feminism are applicable to disability theory. Similar to feminism that faced challenges conceptualizing women as a group (Young, 1994, p.713), disability theorists have struggled with conceptualizing disabled people as a group. Multiple efforts, including that written into the UNCRPD, to identify the attributes of this social assemblage seem to undermine disability rights politics by excluding some people with impairments who should have been included. I discuss this point in more detail in Chapter 5. Here, I believe it is relevant to draw on Young

(1994) to conceptualize disabled people as a collective without implying that all of them have a common identity.

Drawing on Sartre, Young (1994) has suggested the concept of seriality for understanding the relationship of individuals to race, class, gender and other collective structures (p.732). Seriality is a passive, background unity, while groups are self-conscious social collectives (Young, 1994, pp.733-735). In that sense, impairments would serve as a series and the sort of passive unity to which Young alluded. Paraphrasing Young, impairments will mark every impaired individual's life in his or her own way, and each individual's identity is unique (Young, 1994, p.734). Groups have specific purposes around which individuals are united, which makes groups always partial in relation to the series, because they can never encompass the totality of the conditions of even their participating individuals as series (Young, 1994, p.737). Thus, different disability rights groups may arise out of the impairment series, each with their particular purposes, but as Young warns us, they cannot encompass the totality of the condition of impaired individuals.

### **Putting the Framework Together: Democratic Justice**

This section describes the theoretical frame that will guide this study. Among the number of approaches discussed above, I have chosen to combine two that I contend are attractive strategies for addressing social inequality.

First, I adopt Young's description of the relationship between justice and democracy as both instrumental and intrinsic. This stance allows viewing the practice of citizenship as an essential ingredient in a vigorous democracy, as the conceptualization encourages

development of public participation and the conditions that support it. Gould's (2004) view of the relationship between democracy and human rights as dialectical complements this orientation and augments Young's intrinsic and instrumental view of democracy and justice. Thus, democracy, justice and human rights are linked in both intrinsic and instrumental ways. Young's approach to justice as a politics of difference places equality at the heart of social justice.

Second, I employ the capabilities approach, which provides a helpful multidimensional framework to gauge social inequalities across different social groups. While aggregations of individuals with different kinds of impairments manifest (and assert) different needs and it therefore cannot be said that all individuals with impairments should be treated equally, combining these approaches may be helpful in retaining the advocacy potential of people with different disabilities for equal rights while respecting their individual needs.

Young (1990) has developed an ideal model of politics, "as deliberation in a heterogeneous public which affirms group differences and gives specific representation to oppressed groups" (p.260). She (2000) does not restrict deliberation to state actors, but views the imperative as socially inclusive, bringing non-state actors into the discussion. In her view, democratic processes cannot be identified with just one institution or set of institutions (p.46). These insights make Young's approach a particularly attractive one by which to address social inequality, but too abstract, in my view, to allow for the development of specific policies and actions and to craft mechanisms to track and benchmark policy outcomes. Burchardt's case study demonstrated the utility of the capabilities approach in creating a practical and multi-dimensional view of inequality, which can be replicated in other contexts. The capabilities

perspective values the, “dignity, autonomy, and potential of all individuals” (Stein, 2007, p.77), viewing each as an end in herself. This is a particularly compelling vision for disabled people who have been denied autonomy and dignity and opportunities to develop their potential for many decades around the world.

It is also crucial for advancing disability rights and justice to remember that Brazilians with impairments are clearly not a homogeneous social collective: multiple militant groups with various purposes and reflecting diverse individuals struggle to change the power relations in the society between disabled and nondisabled communities. This framework can strengthen disability rights in two ways. First, it would reinforce the idea of participatory democracy as a condition and element of social justice (Young’s approach), of which human rights constitute a crucial part. Second, it can help address substantive inequality among the diverse social groups of individuals with impairments, many of whom are disabled (the capabilities approach).

Recognizing differences within the larger population with impairments is important to compensate for their social disadvantages and to design steps to address their needs and empower them. Furthermore, as Inglehart and Welzel (2005) have pointed out, to make these demands for human emancipation effective, society at large needs to secure advanced socioeconomic rights for all of its members (p.218). In other words, for disabled people to develop effective political participation and exercise strong political pressure, the overarching social fabric must evidence more advanced social and economic conditions to sustain their participation and protesting capacities (p.120). As Chilton and Schaffner (2002) have argued, the practice of politics is closely linked with a society’s culture and language and for that

reason, the study of political discourse can help the analyst to understand socially shared representations of political groups and institutions. I explain my research design and methodological choices in more detail in the next chapter.

## **Chapter 3**

### **Research Design and Methods**

This research explores the meanings that different individuals ascribe to the injustice and exclusion experienced by people with impairments in Brazil. Creswell (2009) describes this perspective as a way of, “looking at research that honors an inductive style, a focus on individual meaning and the importance of rendering the complexity of a situation” (p.4). As this analysis delved into understandings of justice, qualitative research strategies and methods were appropriate to address its basic research questions. Context was highly important in this study, since the conceptions of justice that individuals and groups hold are in considerable measure shaped by their environments.

This chapter consists of four sections. It first provides an overview of the components of my research design, providing a rationale for the choice of a qualitative approach. Second, I describe in greater detail the specific forms of data collection, analysis and interpretation I employed in this analysis. Third, I describe the challenges identified and addressed in this study through the specific research design adopted. Fourth, I share my approach to interdisciplinary integration of different theoretical frames, a type of “cognitive advancement” (Repko, 2008, p.116).

#### **Research Design: an Overview and Justification**

Creswell (2009) has argued that research design is composed of the following components: basic philosophic assumptions, strategies of inquiry and methods of data collection, analysis and interpretation (p.3). I describe my research design components in light

of Creswell's framework. Basic philosophical assumptions can be defined as 'worldviews' that shape the approach taken in the study (Creswell, 2009, pp.5-6). My worldview is underpinned by social constructivist and advocacy epistemologies. Social constructivism holds that individuals create the subjective meanings of their experiences. This orientation inclines researchers to accept a diverse array of views regarding observed phenomena (Creswell, 2009, p.8). When adopting this stance, the analyst's aim is to interpret the meanings that participants offer about the world, while recognizing how the researchers' own cultural, personal and historical background influences the interpretation developed (Ibid). In addition to constructivism, an advocacy approach has shaped my research in that I am dedicated to encouraging public policies that address the needs of individuals with impairments. Many writers have found the constructivist approach by itself to be an insufficient foundation on which to build an action agenda for social and political change (Creswell, 2009, p.9). Denzin and Lincoln (2008), among others, have urged analysts to suggest how the practices of qualitative research can help change the world in positive ways (p.viii). The constructivist and advocacy study frame is congruent with my overall research interests and approach.

Strategies of inquiry constitute a second element of research design. Creswell (2009) has described these as methods that "provide specific direction for procedures" (p.11). I employ ethnography and discourse analysis in this inquiry. Dorsten and Hotchkiss (2005) have observed that the fundamental strength of ethnography is its, "ability to see things that almost certainly cannot be observed using surveys and experiments" (p.123). For its part, critical discourse analysis draws attention to power imbalances, non-democratic practices and social and political inequalities within the specific context of justice issues (in this case,

concerning people with impairments in contemporary Brazil) (see, for example, Fairclough, 1989; Fairlough, 2003; Van Dijk, 2001; Van Dijk, 2002).

Finally, methods constitute the third element of a research design. They involve how the investigator conducts data collection, analysis and interpretation (Creswell, 2009, p.15). Individual interviews with representatives of disability NGOs and individuals with impairments constituted one key form of information collected for this study. Dorsten and Hotchkiss (2005) have underscored the value of direct contact with research participants, particularly in terms of garnering rich detail about people and their interactions (p.123). Every interview provided not only a unique story of life, struggle and engagement, but also helped to shed light on many dimensions and concerns not presently contemplated in Brazilian social policies and claims as these relate to the nation's disabled population. In addition to key informant interviews, I reviewed and analyzed available government and NGO annual reports and websites to explore disability-related justice discourses developed in Brazil in recent years.

A qualitative approach allowed me to focus on the meanings participants assigned to issues, events and concerns. Moreover, an interdisciplinary approach to analysis may help to advance social and political change in guaranteeing justice for impaired citizens. As qualitative research brings together a variety of empirical materials that describe routine and problematic moments and meanings in individuals' lives, researchers need to connect those discoveries to the hopes, needs, goals and premises of a free democratic society (Denzin & Lincoln, 2008, p.4). Creswell (2009) has identified a series of characteristics emblematic of qualitative research including natural setting, inductive analysis, focus on participants'

meanings and interpretations and viewing a problem through a theoretical lens, among several other attributes (p.176). My research design incorporated all of these characteristics. I describe my approach to data collection, analysis and interpretation in the sections that follow.

### **Approaches to Data Collection, Analysis and Interpretation**

In this first part I discuss the procedures of data collection I employed, explaining in particular how I combined key informant interviewing and discourse analysis. Subsequently, I describe my approach to data analysis and interpretation. My study relied on individual interviews supplemented by field notes and analytical memos. I also collected and analyzed governmental and non-governmental organizations' materials as another key source of data. Prior to going into the field, I submitted my project consent form and interview schedule to the Virginia Tech Institutional Review Board for approval. The project underwent full board review since it addressed a vulnerable population and I received approval to proceed in June 2011. The Board's authorization letter and its extension to continue fieldwork in Summer 2012 appear as Appendix A of this study.

**Interview data.** I undertook semi-structured interviews with selected individuals for this inquiry. Triviños (1987) has argued that a semi-structured conversation departs from basic research questions that emerged from existing literature because participants in this type of interview contribute to research content by offering their thoughts and experiences within the principal focus or foci determined by the investigator (p.146). Research questions in this study first emerged with empirical evidence I gathered while working in disability NGOs in Brazil due to a lack of literature in that nation that addresses these issues of injustice.

However, my questions are predicated on the available disability scholarship to enable this study to make a relevant theoretical contribution as well. I conducted 18 individual semi-structured interviews with the representatives of disability NGOs and individuals with impairments in July and August 2011 in Portuguese, in settings selected by study participants, such as public places or their residences or workplaces.

I began my fieldwork by contacting 10 representatives of disability NGOs in the city of São Paulo. I addressed some via email and others by telephone, providing a brief description of my study and inviting them to participate in an interview. Initially, only three individuals responded and offered to set-up in-person conversations. Follow-up efforts with the remaining others did not yield positive results. I therefore went on to contact 10 additional NGOs, seven in São Paulo, two in Rio de Janeiro and one in Salvador. This group resulted in four additional individuals agreeing to interviews, two of them via Skype and one by email. The final result of these efforts was seven interviews with disability NGO leaders. The oral interviews averaged 50-60 minutes each. The session conducted via email took about a week between me sending broad questions and receiving answers (which I thereafter compiled into a single document). Exemplar questions for these interviews appear in Appendix B.

Interviews and contacts with nonprofit leaders and staff gave me access to people with impairments with whom they work in their programs and projects. I intended to interview adults with a variety of disabilities and to ensure that outcome I drew on several organizations for a pool of potential study participants. In addition to disability-related organizations, I contacted the Museum of Modern Art of São Paulo and the Municipal Council of Persons with Disability of São Paulo to expand my group of participants. The former had several art

projects involving deaf youths and the latter organized monthly events for impaired residents at which I could meet and potentially recruit interviewees. As a result of these efforts, I individually interviewed 11 adults with impairments who live/work in São Paulo. These participants had visual, hearing, physical, intellectual and, in some cases, multiple impairments and ranged in age from 19 to 50. My assumption behind diversifying the pool of study participants was that different kinds and degrees of disability entailed varied life experiences. The interviews averaged 50-60 minutes each and took place mostly in residential settings. Sample questions for these conversations appear in Appendix C of this study.

I provided each of my respondents with an electronic copy of the consent form approved by the Virginia Tech IRB, which I translated into Portuguese. Some NGO leaders asked to read my dissertation prospectus in addition to be certain they understood my study aims and to make a more informed judgment concerning providing me access to specific potential interviewees. Ultimately, I had several opportunities to speak to individuals to whom organizational representatives introduced me. On the day of each scheduled interview, I provided each participant two printed copies of the study consent form for signature: one for my records and another for their use. In the two cases in which I conducted interviews via Skype, I obtained signed and scanned consent forms prior to our conversations. In the lone instance in which a participant answered interview questions by email, I received the scanned and signed consent form by email together with the individual's answers. One participant was both visually and physically impaired and unable to read and sign the form. In that instance, I read the text of the consent form to him and recorded his verbal consent to participate on my audio-recorder. The form I employed is included as Appendix D of this study.

I personally transcribed the audio-recorded interviews in the weeks following each conversation. All participants agreed to be audiotaped when they agreed to participate in the study. Even though I promised to honor their willingness to withdraw from taping at any time without any negative repercussions, no interviewee chose to do so. Silverman (1993) has argued, “audio-recordings [are] an increasingly important part of qualitative research” and transcripts “provide an excellent record of ‘naturally occurring’ interaction” (p.10). I shared the interview transcripts I produced with all participants by email or regular mail to allow each an opportunity to check the factual accuracy of the data. I also allowed each interviewee to retain their copy of their interview transcript as they wished. For one visually impaired participant who did not have access to the Internet on a regular basis, I provided a transcript printed in Braille. He was able thereby to review his responses.

I kept field notes as another source of information. In those reflections, I recorded general thoughts and impressions of how well each interview went, the setting of each conversation, how satisfied I was with the conversation’s outcomes, the details I learned from each participant as well as a summary of their situations and perspectives and my initial reactions to those. Later, when transcribing the interviews, those field notes helped to bring to mind some important contextual details regarding each interaction. Sometimes, frankly as a way of venting, I also used my field notes as a venue in which to record the difficulties I experienced with recruiting interview participants: the challenge of persuading individuals to return my calls or emails in a timely manner, for example. During interview transcription and analysis I also prepared analytic memos to record ideas, questions and insights that could be developed later. These brief memoranda were particularly valuable when recording my

findings as they allowed me to look back and check my initial assumptions and/or reconsider my emerging insights (Steinmetz in Ely et al., 1991).

**Reports, websites and other documents.** Governmental and non-governmental organization reports and documents also provided an excellent source of data. Exploring relevant Brazilian public documents concerning recent rights-based policies on the one hand and non-governmental advocacy organizations' reports and websites on the other hand, helped me evaluate whether and how these efforts are contributing to social justice and a more robust Brazilian democracy. The Secretariat for Human Rights compiled Brazil's disability rights-related laws, policies and programmatic actions in a National Report (Relatório Nacional) at the beginning of last year. In April 2011, the government made public a belated draft report for 2008-2010 concerning its progress in implementing the Convention, inviting civil society organization representatives and disabled citizens to contribute documented evidence and suggestions to be analyzed for potential incorporation into its national report to the UN. Brazil submitted the final version of its first attempt to update the United Nations on its efforts to realize the Convention's goals in late May 2012.

**Data analysis and interpretation procedures.** Creswell (2009) has noted that analysis is an ongoing process that involves, "making sense out of text and image data" (p.183). He has suggested that such scrutiny involves a six-step process in which, "the various stages are interrelated and not always visited in the order presented" (p.185). The first two phases entail transcribing and organizing the material and reading through all data to get a general sense of its contents. In my case, transcribing and organizing 18 interviews and 15 reports and translating substantial excerpts into English proved to be laborious and time-

consuming activities. An initial reading of all the material helped me gain a general idea of participants' accounts. Subsequently, as a third step, I undertook a more detailed analysis with a coding process for which I used a combination of predetermined and emerging codes. Preset codes were based on the reviewed literature, while emerging codes arose from the interviews, field notes and memos, reports and documents. I coded all data with the help of NVivo, a software program developed to aid researchers with organizing and sorting information. The coding process generates themes for analysis in Creswell's posited fourth stage. That held true in my case and I actively sought to identify connections among the themes I detected.

According to Creswell, the fifth stage in analysis involves making decisions on how the themes discovered in the data should be represented in the study's narrative (Creswell, 2009, p.189). This proved true for my effort, as I worked to discern language's role in maintaining and changing power relations in contemporary Brazilian society. Drawing on Pierre Bourdieu, Fairclough (1989) has argued, "in discourse people can be legitimizing (or delegitimizing) particular power relations without being conscious of doing so" (p.41). This discursive reproduction of dominance has two major dimensions: the production of various structures of text and talk and their reception and their consequences for the consciousness of recipients (van Dijk, 2001, p.303). Controlling context is one way to enact power, which can be legally or morally illegitimate, because the less powerful are not as often quoted or included in discussions (van Dijk, 2001, pp.303-304). However, members of marginalized groups may still be dominated in discourse, even when present as participants, as van Dijk (2001) has argued (p.304). For disabled people this domination can be easily achieved, for example, by not providing a sign language interpreter for Deaf participants, ramps for wheelchair users or audio description of visual materials or Braille text for Blind participants.

Another way to enact power is to control micro-level forms of text and talk, which is less direct and immediate with subtle and sometimes even unintentional dominating outcomes (van Dijk, 2001, p.304-305). Production of biased discourse may be inadvertent and automatized in which specific social representations of more privileged people are predicated on the condition of legitimation of the privilege and dominance (van Dijk, 2001, p.306). For example, when some nondisabled people deny the existence of any difference between themselves and disabled people, they may intend to articulate a view of equality, but it may also mean they do not believe impaired individuals should have any privileged priority in accessing healthcare, transportation or education to permit them actually to attain the status accorded them.

To expand my understanding of the content of the interviews, I employed critical discourse analysis (CDA) as a way of questioning the basic underlying assumptions, beliefs and attitudes expressed by my respondents. Fairclough (2003) has suggested CDA must be considered a form of analytical social research, which asks questions to gain a better understanding of both beneficial and detrimental effects that societies can produce to affect the lives of human beings as well as how such harmful effects as may be produced can be mitigated or eliminated (pp.202-203). Fairclough (2003) has argued that the importance of language and discourse in critical research is significant since language has become, “a crucial aspect of the social transformations which are going on—one cannot make sense of them without thinking about language” (p.203). As van Dijk (2001) has observed, the power enacted by persuasion or manipulation is mostly cognitive and more effective than elementary recourse to force. In this sense, discourses may be said to manage the minds of those employing them through text or talk (p.302). In examining policymaking dynamics, the

discourse perspective encourages participants to move beyond a simply technocratic conception of policy actions (Fischer, 2003, p.114). This characteristic was especially significant for my study because detailed credible data is not always readily available concerning individuals with impairments.

### **Challenges Identified and Addressed**

This section examines the challenges of qualitative research in general and of disability studies in particular. I discuss in detail the issues of study validity, generalizability and authenticity. I turn first to the so-called “triple crisis” in qualitative research.

**Concerns in the qualitative research.** Denzin and Lincoln (2008) point to several major challenges associated with qualitative research, including the dramatically labeled “triple crisis” of representation, legitimation and praxis (p.26). The representational concern may arise with questioning of a researcher’s capacity actually to capture the lived experience of those they study. Critics of qualitative studies contend the experiences analysts report are created in the social text written by the researcher, rather than constituting a faithful rendering of an occurrence or emotion beyond the author (p.26). To address this concern Lincoln (2008) has suggested, “reformulating relationships between researcher and researched,” to share roles between them and called for, “moral discretion regarding the purposes and representations of social inquiry” (p.239). The second or legitimation crisis involving qualitative inquiry requires seriously rethinking terms such as validity and reliability as scholars have commonly conceptualized these concepts. The normative question implicit in such an effort, for Denzin and Lincoln (2008), is how the academic community should evaluate qualitative studies. I

address these concerns separately at the end of this section. The third crisis these scholars raise is social science's questionable effects on social change (p.27). Lincoln and Denzin (2008) argue that inquiry needs to be reconnected with social purpose as, "social scientists have lost sight of the purposive, intentional meanings of their work, and circled back to their disciplinary roots" (p.542).

I believe these three concerns do constitute significant challenges. They appear especially salient for this inquiry because issues of social justice for the impaired—the coupling of historical structures of oppression with the unjust distribution of social goods and services—are at its core. I turn next to specific challenges faced by disability research that concern representation and legitimacy issues.

**Challenges specific to disability research.** Disability studies as a field of inquiry may be said to manifest multiple dimensions of Denzin and Lincoln's posited representation crisis. First, the level of representation of people with disabilities in academic settings is low, whether as students, faculty or administrators (Linton, 1998b; Longmore & Umanski, 2001). Second, disability-related research is undertaken far more frequently in applied fields with a medical pathological perspective than in the social sciences. Finally, the divide between the 'social' and 'medical' models typically excludes the impaired body from political representation, equalizing impairment with non-impairment (Shakespeare, 2006; Siebers, 2008).

Legitimacy issues also concern disability studies as scholars try to affirm their place outside the medical and applied fields, having to struggle against being viewed as, "an instance of identity politics expropriating academic legitimation and resources to promote the

personal self-esteem and parochial political agenda of a narrow interest group” (Longmore & Umanski, 2001, pp. 8-9). However, MacIntyre has argued that disability, “is not a special interest, the interest of one particular group rather than of others, but rather 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).

The extensive debate among disability studies scholars concerning appropriate paradigms, theories and methodologies to advance knowledge production regarding impairments and to inform disability social movements in different countries, appears to be undermining their legitimacy with scholars outside their own field. The ‘social’ model of disability on which disability studies is based has, for example, been strongly criticized as outdated and inappropriate for the current historical moment (Shakespeare, 2006; Siebers, 2001; Siebers, 2008). And finally, in terms of the relationship of disability analyses to social change, disability studies’ attempts to accommodate the diverse needs and views of the community the field examines have created difficult paradoxes. As Shakespeare (2006) has pointed out, just because an individual has an impairment, does not mean that person can offer insight into the lives and experiences of other disabled people, since disabilities and experiences are so diverse (p.195). As the same noted analyst has also observed, “Ending disablism—the unfair discrimination against disabled people—will not solve all the problems of disabled people” (Shakespeare, 2006, p.65). There is a real need for constructive collaboration between proponents of impairment-based and disability-based approaches (Corker & French, 1999; Schillmeier, 2010; Shakespeare, 2006; Thomas, 2004).

The concerns addressed by disability research scholars underscore the ‘invisibility’ of the perspectives and interests of disabled people in academic inquiry more generally. That observation seems to hold particularly true in developing countries with high illiteracy rates and poverty among disabled people. Thus, from the outset, I sought to ground my research questions in the lives of disabled people to ensure that my work would contribute not only to academic and practical knowledge, but most importantly to serve those people as they go about their daily lives.

My inquiry addresses the disability studies literature in two basic ways. First, the critique by many scholars concerning the lack of empirical concerns incorporated into disability research and the dearth of voices of disabled people in such analyses is addressed here through two strategies. Available statistics highlight the shocking level of educational, economic and social exclusion of disabled Brazilians and, it seems clear, a lack of consistent public policy perpetuates those disadvantages. Thus, my research addresses an empirical concern regarding the lack of social justice for the disabled community in Brazil. In addition, ethnography is a crucial part of my inquiry, and I employ it explicitly to examine the disability-related knowledge, experiences, existing discourses and local practices in place in field settings. Analyzing the meanings disabled people attach to their impairments as well as what they believe would constitute just treatment permitted me to gain a deeper understanding of the assumptions underlying the disability and justice discourses currently being generated and reproduced in contemporary Brazilian society. That knowledge will contribute directly to the ongoing controversy in the field concerning how it might most appropriately be defined.

Shakespeare has raised the issue of nondisabled researchers examining disability-related concerns as a potential obstacle to such inquiry. I also see this as an ethical concern, but it is one that can be readily addressed in my view. I agree with Shakespeare (2006) that, “the idea that having an impairment is vital to understanding impairment is dangerously essentialist” (p.195). This issue has to do more with the ethical stance of the researcher than with being disabled. As Bailey has observed, “Ethical considerations permeate every aspect of the field research process, from selecting the research topic to disseminating the results” (Bailey, 2007, p.15). Several years of working and socializing with individuals with impairments have allowed me to develop a general understanding of their experiences and struggles. I believe the key is to demonstrate through my values and attitudes that I have an interest in the social situation of disabled people and more particularly, in improving their living conditions. Also, I believe that my ability to empathize, to understand the world from another’s perspective, is valuable in dealing with ethical concerns, in order, as Friedman put it, “to be open to mining one’s emotions for their intellectual lessons” (Friedman in Ely et al, 1991, p. 136).

**Generalization, validity, and authenticity.** Luker (2008) has distinguished between generalizations made in quantitative and qualitative studies. In quantitative research, “a logic of verification,” or “theory testing,” provides the conditions for generalization, while a “logic of discovery” or “theory generating,” sets such conditions in qualitative studies (p.125). She suggests a compelling way to pursue generalization in such analyses can occur by “bump[ing] up a level of generality” and aspiring to “the most abstract level” in the research study (p.126). Luker has argued that engaging in this sort of qualitative analytic work may benefit a study in two ways: first, by drawing a much wider audience than that interested in one

particular area and second, relating to, “other studies that think about things on this same level of abstraction” (Ibid). Luker’s suggestion relates well to Roth’s claim that any putative knowledge, “is to be judged in regard to how it integrates with what else passes as knowledge” (cited in Lincoln & Denzin, 2008, p.542).

Luker’s observation concerning the relationship of abstraction and generalization informed the design of this study in several ways. First, the conceptual framework reviewed in Chapter 2 provided several theoretical lenses that help analyze and interpret empirical claims about what citizens with impairments and their advocates want. Second, my analysis proceeds through levels of abstraction, from empirical claims to their materialization in social policies, to their further implications for advancing human rights and promoting social justice and democracy on a more general level. Third, the interdisciplinary approach discussed in the next section brings together insights from democratic, political and social justice theory and disability studies in an effort to understand better the conditions that advance social and political change for the disabled. Finally, my concluding chapter (chapter 8) interprets my study findings through alternate theoretical lenses.

Validity has varied meanings for scholars engaged in qualitative research. For Creswell (2009), qualitative validity denotes concern with the accuracy and credibility of findings (p.190). He suggests using several strategies both to enhance the researcher’s assessment of the accuracy of conclusions and to assure readers of their veracity (p.191). Of Creswell’s suggested strategies, three seem particularly applicable to my research: data triangulation, ‘thick’ description and clarification of researcher bias. I discuss these next below. Creswell also suggests member check-in as a strategy to improve study validity, but I

found it difficult to adopt it for this effort. Because all my writing for this effort has been in English, to allow interviewees to validate its accuracy would require that I translate all I have written into Portuguese. To do so is simply unduly time and resource consuming at this point. Nonetheless, I do plan eventually to translate my finished work into Portuguese and disseminate it in Brazil, but I do not think spending time trying to do so at this stage would prove especially useful to anyone.

Data triangulation involves examining evidence from several sources or participants, when themes emerge from multiple founts. Creswell (2009) claims that if arguments are established coming from several sources, then this process can be claimed as enhancing the validity of the study (p.191). For example, political participation of the disabled emerged across multiple interviews and NGO websites as a crucial theme, which I discuss in Chapter 6. Furthermore, in this study, ‘thick description’ means providing not only rich detail concerning the setting and context of the work, but also several perspectives on the key themes that arise from it, which I have done in Chapters 4-7. Creswell (2009) views this procedure as adding to the validity of qualitative analytic findings (p.192). Finally, constant reflection has helped me to be as self-conscious and open and transparent as possible, concerning how I developed my interpretation of this study’s analysis and conclusions. The next section discusses another layer of self-reflection: integration of various disciplinary insights with the intent of ultimately producing an interdisciplinary understanding of the questions I investigated.

Several disability studies scholars have analyzed the issue of the validity of disability-related research. Oliver, for instance, has challenged the field’s validity from the perspective

of the epistemic paradigm that underpins it, calling for a change in the discourse from “research as investigation” to “research as production,” thereby developing a “truly emancipatory research paradigm” (Oliver, 1999, p.183). Similarly, Linton (1998a) has questioned the validity of generated research when not informed by disabled peoples’ perspectives (p.78). This study addresses these concerns by adopting the constructivist and advocacy paradigms discussed earlier in the chapter and by engaging directly with viewpoints offered by members of the disabled community.

Silverman (1993) has raised the issue of interview ‘authenticity’ as one of the “unresolved debates about the status of interview accounts” in qualitative study (p.15). As he has noted, “The aim is usually to gather an authentic understanding of people’s experiences and it is believed that open-ended questions are the most effective route towards this end” (Silverman, 1993, p.10). My interviews were underpinned by open-ended exploratory questions, and I sought to gather diverse perspectives, encouraging respondents to offer their own definitions and meanings of their experiences. Respondents’ knowledge of social structures in producing what Silverman (1993) calls “locally ‘adequate’ utterances” (p.104) gave me access to “the repertoire of narratives” used in producing accounts, which “are part of the world they describe” (Silverman, 1993, p.108). My main interest was in discerning how the particular conceptions of participants were constructed rather than with true or false representations of participants’ attitudes and behavior. Like Silverman (1993), I treated my “interview accounts as compelling narratives” (p.114).

## **Interdisciplinary Integration**

Both Klein (1990) and Repko (2008) have argued that there is no single way of undertaking interdisciplinary research. For his part, Repko (2008) has discussed several key features of such inquiry, particularly its heuristic and reflexive character (p.137). It is a heuristic because it provides a way of understanding a complex problem that a single disciplinary perspective would be limited in achieving (p.138). Interdisciplinary investigation is reflexive, as it demands being self-aware and self-disciplined concerning personal and disciplinary bias, which could affect the process of evaluating the insights provided by different frames, and ultimately, the product of their integration (p.139). Thus, interdisciplinary research poses additional potential challenges to research validity.

I supplemented the procedures I gleaned from Creswell (2009) to enhance the validity of this study with careful analysis of the problem from alternate disciplinary perspectives. The overarching question posed by each discipline and its corresponding theories not only embodies its unique perspective, but also helps reveal subject bias in both the questions and responses it yields (Repko, 2008, p.219). After clarifying and analyzing each disciplinary perspective, Repko (2008) has proposed a series of steps to achieve interdisciplinary understanding: identifying where disciplinary insights conflict, searching for common ground among those, which serves as a basis for their integration and ultimately producing a fresh understanding of a problem (p.247). However, my ultimate purpose is not to diminish disciplinary differences by focusing on common ground, but to create dialogue and negotiate the differences arising from alternate meanings of justice for disabled people. The concluding

chapter of this study reflects such an effort, leaving the ambitious project of promoting justice and guaranteeing disability human rights (appropriately) open-ended.

## **Chapter 4**

### **Dimensions of Injustice toward Disabled Citizens since Brazil's Modern Democratization**

This chapter provides background information on the issues and tensions implied in Brazil's democratic institutions. Brazil's democratization has been uneven: the nation continues to evidence a continuing lack of empowerment of the poor, widespread government corruption and substantial social inequality that undermines the exercise of citizenship by its marginalized groups. I discuss the historical, social and political context in Brazil since its formal turn to democratization in 1988 to the present day, ending with an overview of the dimensions of injustice experienced by disabled citizens. This background information helps to contextualize the human rights policies of the Brazilian government discussed in Chapter 5, strategies and actions of disability NGOs discussed in Chapter 6 and the conceptions of justice of individuals with impairments discussed in Chapter 7.

#### **Historical Background: Democratization and Citizenship Development in Brazil<sup>5</sup>**

This section begins with a brief overview of the process of democratization in Brazil in recent decades and the place of civil society in that process.<sup>6</sup> Democracy was restored formally in Brazil in 1985 when civilian government was re-established after 21 years of military dictatorship. However, simply turning to a non-military government did not automatically result in the re-creation of democracy in the nation. Democratization has occurred gradually and unevenly. Elections were held first municipally, then at the state level and finally, after several years, nationally (Levine, 1999, p.138; Fausto, 1999, p.317). It took

the nation from 1974 to 1987 to transition from a military authoritarian regime to a civilian democratic one. This slow and gradual “opening” had the advantage of not creating great social upheaval, but it did not address the underlying social and political problems, such as existing social inequality, corruption and political patronage (Fausto, 1999, pp. 318-19).

Freire (1973) has discussed the case of Brazil’s “fundamental democratization,” its transformation from object to subject society, criticizing those with much power for deploying the politics of assistencialism to contain the potential for social change and to continue to treat recipients (citizens) as passive objects (p.15). Freire saw the greatest danger of assistencialism in the violence of its anti-dialogue, which, by imposing silence and passivity, denied men and women the conditions likely to allow them to develop, or to “open” their consciousness” (p.15). Furthermore, assistencialist politics robbed individuals of responsibility, which made democratic possibility difficult to achieve (p.16). In Brazil’s transition, Freire pointed to the denial of dialogue in favor of decrees that made society mute and silent, by which he meant lacking in critical response. According to Freire (1973), Brazil set out to inaugurate a formal democracy on the basis of a, “vast lack of democratic experience, characterized by a feudal mentality and sustained by a colonial economic and social structure” (p.28). Democracy was an imported idea for Brazil, a superimposed solution for a people with no experience in self-government (Freire, 1973, pp.28-29).

The new Constitution, enacted in 1988, was the nation’s seventh since gaining independence from Portugal in 1822,<sup>7</sup> and the public widely perceived it as the backbone of the democratization process, to which the social movement of people with impairments contributed greatly (Lanna, 2010). Brazilians expected the new Constitution to ensure the

social and political rights of all citizens (Fausto, 1999, p.316; Sposati, 2004, p.50). Indeed, the National Constituting Assembly (1987-1988) was surely the most democratic gathering of its type in Brazilian history. The Assembly provided multiple open and legitimate channels for popular participation (Lanna, 2010, p.34). The Constitution adopted human dignity as one of five fundamental principles of the Republic (Art.1),<sup>8</sup> intending to provide a framework for, “constructing a free, just, and solidary society” that promotes everyone’s wellbeing without prejudice (Art.3). Any kind of discrimination on the basis of national origin, gender, race, color, age or for other reasons was declared unlawful. However, racial discrimination is still a complicated issue in Brazil, evident in educational and work opportunities, and few practical advances have occurred even as a sizable chunk of the population denies that racial discrimination exists (Fausto, 1999, pp.336-37; Levine, 1999, p. 155).

In an attempt to decentralize state power, the Constitution transferred a significant share of national income to states and municipalities, while placing the responsibility for major social programs with the Federal government (Levine, 1999, p.138; Fausto, 1999, p.316). The principal problem with this arrangement was a lack of built-in accountability mechanisms and ways to improve the effectiveness and efficiency of social programs. The decentralization, delegation and electoral changes implemented in the late 1980s revealed corruption and mismanagement at all levels of government (Levine, 1999, p.139) while doing little to change the system of political patronage at all scales that had long typified the nation’s politics. The new regime highlighted a basic paradox for Brazil: is it possible to change public and political life by designing and enforcing laws and governance structures while not changing the network of personal connections, norms and values that constitute the fabric of political and institutional life? (DaMatta, 1986, p.121)

Meanwhile, political scientists criticized the new Constitution as creating a rigid and fragmented process of lawmaking in Congress, a drawback observed by many disability advocacy NGO leaders I interviewed as well. The Constitution also provided a very large legislative role for the president but did not give the judiciary independent power to review the constitutionality of the nation's laws (Levine, 1999, p.144). The most remarkable power in the new Constitution was that assigned the President to legislate through provisional decrees, which allows the chief executive to enact new legislation promptly and without congressional approval. Hagopian (1990) has labeled this provision, "a mockery of the virtues of [the] liberal democracy" (p.154). This power not only gives the President the ability to legislate, it also allows him to influence, if not determine, the congressional agenda (Alston, Melo, Mueller & Pereira, 2006, p.18).<sup>9</sup> The Constitution also handed the President the power to veto Congress' legislation completely or partially, but the charter offset this provision by making it relatively easy for the legislature to override the chief executive's veto. Nonetheless, that does not happen often (Alston et al., 2006, p.19). Although the Constitution gave some oversight functions to the legislature and judiciary, this power is not often employed effectively (Ibid).

Evaluating the extent of political and social democracy developed in Brazil since 1988, contemporary scholars have noted promising trends on the one hand, and "disenchantment with democracy" due to a continuing lack of empowerment of the poor and continued corruption, clientelism, and weak political participation by the nation's youth, on the other hand (Perlman, 2011, p.48; Melo & Saez, 2007). Much remains to be done to reduce the deficit of representation and accountability and to enable poor citizens and marginalized groups to take full advantage of their formal rights (Melo & Saez, 2007; Perlman, 2011, p.57). Perlman has argued that in order to deepen democracy, the existing enormous inequality that

undermines the exercise of citizenship by the poor, should be addressed. Perlman has quoted U.S. Supreme Court Justice Louis D. Brandeis, who said, "We can have democracy in this country [the US], or we can have great wealth concentrated in the hands of the few, but we can't have both" (p.57). Hakopian (2007) has contended that weak support of democracy in Brazil can be partially explained by the nation's poor record of civil rights protection (p.51).

Political participation became relevant in Brazil in the mid-1980s when subaltern social groups began to view democracy as more than a simple set of rules governing formal engagement in public life. Instead, these populations increasingly perceived politics as a process of rights building, in which different social groups 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," in which relationships define the social order (Levine, 1999, p.153). New citizenship rights clashed with existing social norms and rules of membership in various groups, defined by gender, race, political affiliation, occupation and place of residence (Levine, 1999, p.154). Social distinctions implied differential treatment by police, judiciary and legal institutions. The high-minded rhetoric of universal rights of the new Constitution contradicted these long-standing norms and values. However, Levine (1999) has cautioned against rushing to judgment concerning Brazil's uneven democratization process and argued that universal citizenship is a relatively recent attainment even in the Western democracies (p.157). Indeed, within a decade following adoption of the new democratic Constitution, Brazil's government began work on policies and actions to incorporate human rights into its agenda.

The development of citizenship in Brazil has been uneven across social groups (Holston, 2007). Historically, the franchise in the country has been rooted in difference and differential treatment of specific social groups and, once conferred, it became their private privilege (Holston, 2007, pp.87-88). Citizenship was nominally extended to subaltern classes in the 1930 revolution with the provision of social rights to workers, and some privileges granted workers at that time, such as a 30-day paid vacation and social security, tax exemptions and other privileges have been written into law and remained in force (Levine, 1999, p.156). These rights did not originate from a set of political values, but from a system of occupational stratification, defined by extending citizenship only to workers whose occupation was recognized and defined legally. In this way, the state reinforced existing occupational inequalities, transforming them into inequalities in rights (Sposati, 1986, p.36). But this action was also motivated by another agenda regarding informal workers. By extending the benefits of citizenship only to formal workers, the state intended to discipline and motivate informal sector entrepreneurs to move to the formal sector, since a significant part of the workforce was and continues to be informal in character (Sposati, 2004, pp.12-13). This effort and continuing predilection has very serious implications for adults with impairments, the vast majority of whom are either self-employed or employed informally. Not only do they receive significantly lower pay, but they also lack effective political rights.

The government has extended citizenship to more people in Brazil in recent decades, even as that regime has legitimized the collective exclusion of the popular classes from the enjoyment of many political rights (Nunes et al., 1982, cited in Sposati, 1986, p.37). This attempt by national officials to parse who could exercise citizenship has clashed with provisions of the liberal Constitution of 1988, which has at its foundation a formal conception

of citizenship as fixed in individuals as autonomous holders of universal political and social rights. However, the continuing importance of citizenship as a privilege of formal sector workers has hindered the economically dependent and subaltern classes from realizing their rights under the Constitution. Indeed, perhaps the greatest challenge posed to Brazilian democracy today is the nation's continuing inability to secure the universal application of citizenship rights, as Levine (1999) has pointed out (p.156). This situation has only been exacerbated for the disabled by a neoliberal emphasis on ensuring the economic efficiency of healthcare and social security since the 1990s. That orientation has generated a damaging attitude toward impaired citizens in Brazil, in which many citizens and lawmakers view them as unproductive burdens to society, unemployable and incompetent. The failure to extend rights universally and the decision to tie them instead only to specific situations resulting in the broad social labeling of some people as incompetent and unemployable, weakens the foundations of democracy (Levine, 1999, pp.156-157). Many young Brazilians today consider rights as something that are not given, but earned by conforming to social norms, "citizenship does not confer rights, rather having rights defines being a citizen," suggesting a temporary and conditional conception of rights (Ibid). In the case of people with impairments, this implies they must earn their rights by demonstrating their "merit" in education, the workplace and social life.

Voting is likely the primary expression of political citizenship for disabled Brazilians. They are not required to vote by the current Constitution (while it is compulsory for all other citizens), which also does not demand that polling sites be accessible for the physically and visually impaired. To ensure the possibility of exercising their right, disabled voters who need special conditions must register with the authorities months before scheduled elections, so

they may be directed to an accessible voting site in their city or town. This example illustrates the clash between equal rights to all guaranteed by the Constitution and membership in a social group viewed largely negatively—in this case, the disabled population—leaving a significant gap between abstract political rights and the actual capacity/opportunity to realize those rights for these citizens in daily life.

The Brazilian government began actively to pursue a human-rights-agenda in 1996 with the launch of the First Human Rights National Program (*Programa Nacional de Direitos Humanos*). The Second Human Rights National Program revised and broadened the nation's rights related policy agenda in 2002. The new effort included protections and guarantees of economic, social and cultural rights (Relatório Nacional: Relatório Geral, §32). The Third edition of the Program, HRNP-3, adopted in 2008, underscored the importance of “transversality and inter-ministry effort” in realizing its strategic objectives and program actions. That Plan included more than 500 programmatic actions across all 31 major federal ministries, state agencies, legislative and judicial organizations. HRNP-3 reflected a universalist perspective and stressed the interdependence of rights and their implementation (Relatório Nacional: Relatório 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 HRNP-3. Some 14,000 people from civil society and government organizations alike were involved in local, regional and national Conferences on Human Rights to generate input for the National Conference on the topic (Relatório Nacional: Relatório Específico §40). HRNP-3 incorporated policies and programs specific to the disabled population.

The government also adopted Plan 2022 in 2010. The initiative strategically outlined goals and objectives the Federal Administration and Brazilian society should promote for the full realization of rights for all of the country's citizens by 2022, when Brazil will celebrate its bicentennial as an independent nation. Plan 2022 seeks not only to assure attainment of equal rights for both disabled and nondisabled citizens, but also to ensure specific rights for the impaired that make it possible for them, whatever their condition, to enjoy a fulsome life (Relatório Geral §73). Ambitious and comprehensive, the Plan was carefully negotiated with many politicians across political parties so as to have wide support for its 150 goals and objectives. However, the Plan lacks accountability mechanisms and nearly two years after its enactment, my online search through government documents and media webpages revealed no formal update or public statement of progress regarding its targets.

Another example of a recent public policy is the major social program of the new government launched in 2011, called Brazil without Misery (*Brasil sem Miséria*). Nonetheless, as one disability rights activist told me in an interview, national public officials conceived the program without including disabled people in its target population.<sup>10</sup> It is well known among scholars and practitioners that people with impairments and families with members who have disabilities are highly susceptible to poverty (UN, n.d.; Sen, 2004). The new social program targeted the 16 million extremely poor Brazilians in an effort to lift them out of poverty before 2014. The program's 1<sup>st</sup> year report<sup>11</sup> argued that it had assisted 687,000 extremely poor families through income transfer, education, healthcare services and work qualification, but it did not mention the numbers of people with impairments or their families who had benefitted from its actions. According to my interviewee, to take action against poverty and injustice that assists disabled people, the government must make investments and

take coordinated actions to support their families, to help them generate income when appropriate, to include them in schools and to extend to all those requiring such support, accessible healthcare and rehabilitation. The population with impairments should likewise explicitly be included in such efforts when such a policy is devised for the most disadvantaged.

On November 17, 2011, the Federal government launched its National Plan for the Rights of Persons with Disability, Living without Limits (*Viver Sem Limite*), which contained the nation's proposed strategic actions for the disabled in the areas of education, health, citizenship and accessibility. The most recent national Census in 2010 showed that there are more than 45 million Brazilians with various disabilities, which corresponds to almost 24 percent of the population. With this Plan, the government formally embraced efforts to promote the social inclusion and autonomy of disabled Brazilians by removing barriers to their exercise of their rights and by promoting their access to goods and services.<sup>12</sup>

### **Dimensions of Disability Injustice**

Historically, the structure and responsiveness of Brazil's social welfare system has varied depending on the cultural and political standing of the segment of the population claiming protection: it was universal for the rich minority, unevenly available to members of the working and middle classes and denied to the poor and marginalized population (Biehl, 2005, pp.46-47). In the 1990s, the deinstitutionalization of the mentally ill took place, and community- and family-based psychosocial care came to replace institutions, which resulted in shifting available aid from state institutions to families and communities, but with little

funding allocated for these community-based services (Biehl, 2005, pp.47-48). Many pastoral and philanthropic institutions assumed a share of the responsibility for the caregiving role in the wake of Brazil's democratization and fast-paced neo-liberalization (Biehl, 2005, p.48). In the face of growing unemployment, the rise of the drug economy and generalized violence, many families responded to the growing burden of care occasioned by the new framework by "redefining their functional scope and value systems" (Ibid), meaning refusing to care for their loved ones, which affected the lives of many Brazilians with impairments living in poverty. Many of them were unable to support themselves and ended up in the streets or in philanthropic institutions.

Several factors have contributed to the complex injustices that frame the lives of individuals with impairments in Brazil. Disability injustice is a multifaceted phenomenon, tied to perceived social deviance and the stigma attached to such status and aggravated by the lack of political participation by disabled citizens. As one disability rights activist observed in an interview with me, "Until they have effective participation [in public spaces], it will be difficult to change the rules of the game. It is hard to effectively promote changes to improve life conditions of disabled people while they are not present in decision-making processes."<sup>13</sup> According to recent World Health Organization (WHO) reports,<sup>14</sup> approximately 15 percent of the world's population, or 1 billion people, live with impairment(s) and the great majority of these individuals reside in developing countries,<sup>15</sup> which typically offer little or no support to them. The reasons for the growing numbers are diverse, but WHO suggests the growth is due to population aging, trends in health conditions and environmental degradation, among other factors.

In addition to the relative dearth of reliable statistics for this population in Brazil, when government agencies or NGOs conduct surveys concerning people with impairments, they collect the views and perceptions either of institutions that provide services for the disabled or governmental agencies, rather than of the disabled themselves.<sup>16</sup> The Brazilian Senate and the Brazilian Institute for the Rights of People with Disabilities (IBDD), a nonprofit organization operating in Rio de Janeiro, surveyed the opinions and perceptions of people with impairments concerning their rights, living conditions and policy priorities for the first time in 2010.<sup>17</sup> The poll revealed that of more than 1,000 people interviewed across Brazil, 77 percent did not believe their rights were respected.

The cultural manifestation of disability injustice may be seen in how Brazilians view difference. Charlton (1998) has suggested that, “we ... respond to the human differences between us with fear and loathing and ... handle that difference in one of three ways: ignore it, and if that is not possible, copy it if we think it is dominant, or destroy it if we think it is subordinate” (p.25). These three ways of living with difference are reflected in the survey mentioned above. The dominant perception among people with impairments in Brazil (59 percent of those surveyed) is that prejudice towards them has diminished in recent years; 31 percent think it has stayed the same and 10 percent said it has increased.<sup>18</sup> The survey found that the prevailing perception among those questioned is that wider Brazilian society is seeking to construct a new way to relate to people with impairments, with less discrimination, but there is still much to do. As one advocacy NGO leader commented, “the prejudice seems to diminish, becomes more subtle, we become politically correct, but in essence we continue being a society of prejudice.”<sup>19</sup> I am not aware of any existing qualitative studies concerning discrimination toward individuals with impairments in Brazil, but the diminished level of bias

that this study found may be attributable to more information available and more convivial experiences the society is having with individuals with impairments. However, it was clear to all of the NGO leaders with whom I spoke that this barrier cannot be eliminated by means of law(s) alone. Instead, many collective actions sustained over a significant period will be needed to diminish discrimination and prejudice substantially in contemporary Brazilian society.

Brazil's governments at all levels collect as much in taxes as the U.S. and Great Britain on a proportional scale, but spend most of that sum addressing needs other than those of the poor or otherwise disadvantaged (Levine, 1999, p.150). For example, approximately 60 percent of the educational budget of the nation's governments at the beginning of the 1990s benefitted public universities, which were predominantly accessible to the upper classes (Fausto, 1999, p.328). In 2010, this share had fallen to 51 percent (Veja, 2012). This situation perpetuated the privileged status of the educated elite in terms of the economic, social and political pressure they are capable of exerting on government officials. Thus, a quality education has been a privilege rather than a universal right for young people of all social classes for decades in Brazil (Fausto, 1999, p.329). The national government enacted a new law in Brazil in August, 2012 that promoted so-called "social quotas" for students coming from public high schools—50 percent of the seats at the federal universities have now been reserved for such students beginning in 2013. This new measure is meant to democratize the access of the lower classes to public high school education, although it has been strongly criticized as negatively affecting the quality of such institutions. In the long run, this measure is likely to benefit students with impairments at least marginally since the majority of that population study in Brazil's public school system.

The education-related disadvantage of Brazilians with impairments is visible in the following statistics: while 61.1 percent of the population with impairments 15 and older had no education at all or had incomplete elementary education, this percentage was 38.2 among the population without impairments, an almost 23 percent difference.<sup>20</sup> In 2010, on average, only 8 percent of Brazilians had completed high school education, according to the recent Census:<sup>21</sup> 6.7 percent of those had impairments while 10.4 percent did not have impairments.<sup>22</sup> This suggests that only a small minority of youths with impairments get an opportunity to complete high school, and even fewer will access higher education.

Economic injustice towards people with impairments is evidenced in the following statistics revealed in the nation's 2000 Census, nine million disabled adults were involved in some kind of economic activity, but only 300,000 were formally employed. The rest were either working informally or engaged in some necessity-driven entrepreneurial activity. In 2010, only 0.7 percent, or 306,000 people with impairments out of 44 million formally employed Brazilians, held a job, showing little advance from the previous decade (RAIS, 2010). In 2010, the Ministry of Labor and Employment's report revealed that formal employment of both disabled and nondisabled adults provided compatible average salaries (RAIS, 2010). However, adding gender bias to disability bias, disabled women earned 70 percent of what disabled men earned, while this ratio was 83 percent for women without impairments (RAIS, 2010).

The formal employment of individuals with impairments became a compulsory measure two decades ago through the Law of Quotas for companies of 100 employees or more. Not only did these individuals need to demonstrate the severity of their impairment as

stipulated by the Law, but they also were required to participate in a governmental habilitation / training program. While the statute was an important step towards potential economic independence for this population, the policy is concentrated on the demand side as it is aimed at recruiting more disabled people formally for market sector positions. Representatives of business firms have claimed in the past that this population lacked even basic education and skills to perform responsibilities more involved than low-level jobs. Actions to address both the educated supply of impaired citizens and demand for their services are more appropriate for Brazilian reality, since the gap in education and professional preparation and remuneration of the disabled and nondisabled people is significant. Despite the Law of Quotas that assures a percentage of their number employment in medium and large enterprises, people with impairments have been facing prejudice and a lack of willingness among employers to include them and consider their careers seriously. A recent survey conducted by *i.Social* (a consulting firm) showed that adults with impairments still have few opportunities in the job market and that employers focus more on conforming to legal quotas for disabled employees than on their economic empowerment.<sup>23</sup>

This situation exists despite the human rights aspirations of Brazil's Constitution and the nation's ratification of the UN Convention in 2008. The Convention requires Brazil to develop and enact laws and carry out policies and administrative measures aimed at securing the rights of the disabled. Article 27 concerning work and employment, for example, obliges signatories to take, "appropriate steps, including through legislation...[to] [p]romote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting [of] one's own business" (UN, 2006). Prompted by this language, a law to promote entrepreneurship and establish specific financing opportunities for disabled adults has been

under consideration in the Brazilian legislature for more than three years.<sup>24</sup> The fact that it has languished suggests that many in the legislature do not view efforts to help secure self-employment and entrepreneurship opportunities for the physically disabled as important policy priorities.

Carefully devising policies and initiatives that stimulate and facilitate entrepreneurial activity within the population with disability and encouraging entrepreneurship among women will have many long-lasting social, economic and political effects on Brazil's future. On average, for every two opportunity-driven entrepreneurs in the nation there was one necessity-driven entrepreneur in 2010, that ratio being lower for entrepreneurs with lower incomes and higher for those with higher incomes.<sup>25</sup> Since disabled people have on average less than 4 years of schooling, economically empowering this population through entrepreneurial activity, whether need-or opportunity-driven, will offer them a chance to gain a measure of social inclusion and perhaps extend that chance to others as well.

Disability injustice is also revealed when one examines the right to education of people with impairments. The Convention emphasized equality of opportunities and equality in access to education for disabled persons. However, as the Brazilian 2010 School Census revealed, only 12 percent of elementary schools and 30 percent of middle and high schools are physically accessible for schoolchildren and youth with impairments.<sup>26</sup> Vocational training has been given little priority in existing policies and public investment, which is vitally important for successful employment of people with disabilities.<sup>27</sup> In 2010, fewer than 2,000 people with disabilities were enrolled in vocational training programs in Brazil (Reicher & Atalla, 2011, p.6).<sup>28</sup>

This account of the educational, economic, cultural and political injustices experienced by disabled people in Brazil would not be complete without recounting a story of social abandonment brought to light by João Biehl (2001) in the South of Brazil. In that region, marginalized Brazilians with HIV/AIDS, with impairments, with drug addiction and with mental illnesses, have been “deposited” as “life’s leftovers” (Biehl, 2001, p.131) into a charity institution called Vita, by their families or city/state institutions for the rest of their lives. Biehl’s (2001) powerful account described how these human beings have been “animalized” while spending their last days in inhumane conditions. Moreover, he examined how state institution bureaucratic procedures and the moral choices of many families contributed to the social invisibility of these people and what he calls their “socially authorized death” (Biehl, 2001, p.133). Vita residents had not died biologically, but they were dead socially, and the families and relatives of those brought to the facility as well as area police, hospitals and psychiatric facilities all de facto colluded to absolve society from direct legal accountability and responsibility for the care of those destined for collective death at the location (Biehl, 2001, pp.134-135). Tragically, as Biehl (2001) observed, “Vita is a microcosm of Brazil” (p.135) and across the country one can find similar places in which people have been abandoned to suffering and ultimate death (p.137).

Iris Young’s (1990) account of oppression (pp.39-65) is helpful for understanding the structural oppression that Brazil’s disabled people experience as a group. Young helps frame and draw together the many instances of injustice I presented in this section. Her work shows how oppression inhibits the ability of the disabled, marginalized and powerless to develop and exercise their capacities rendering them very often, culturally dominated and violated. For Young (1990), oppression is a structural concept, not a result of a few people’s choices, but a,

“disadvantage and injustice some people suffer [...] because of the everyday practices of a well-intentioned liberal society” (p.41). Sometimes even unconscious assumptions and attitudes go unquestioned, such as assuming, for example, that blind people cannot create or appreciate visual arts. Young argues that adopting new laws and policies or changing the rules cannot eliminate structural oppression because, “oppressions are systematically reproduced in major economic, political, and cultural institutions” (Young, 1990, p.41). For example, deciding to make available only a certain percentage of all library books as audiobooks or books in Braille significantly limits the reading choices of blind people, as having only a few programs on public television with a sign language interpreter limits the viewing choices of deaf people. The cost-benefit rationale that underpins these decisions limits the access that disabled people as a group have to culture, education and politics.

Many people with impairments are marginalized when they are deprived of meaningful participation in social life and may suffer serious material deprivation as a result. Young (1990) viewed this as, “the most dangerous form of oppression” (p.53). When public places are not accessible, either physically or socially, impaired people are deprived from going out for work, school, leisure, civic duties, etc. Lack of accessibility marginalizes them from the broader society of which they are nominally a part. Millions of these individuals are also powerless, as professionals, particularly medical doctors, decide on social security benefits, rehabilitation processes or the ability of impaired individuals to qualify for employment. Often, disabled people cannot challenge this power and that reality perpetuates a cycle of powerlessness. Having an impairment also limits access to higher education in Brazil as I noted above and that situation makes it less likely that those affected can embark on

promising careers and that fact inhibits their ability to pursue “progressive development of capacities and avenues for recognition” (Young, 1990, p.57).

In diverse ways, in short, society frames the differences between the impaired and those who are not as somehow connoting and persistently reinforcing the deviance and inferiority of the impaired (Young, 1990, p.59). Consider, for example, the experience of deafness in a dominant hearing culture. The divide is stark when one reflects for a moment on the place that sound, speech and music occupy in the ascendant society. This situation can occasion familial choices that impose large costs. One of my deaf interviewees, for example, commented that his hearing family repressed his use of sign language at home and at school, forcing him to use oral language, which made learning and communication more difficult for him.<sup>29</sup> This was probably the experience of thousands of deaf children growing up in hearing families. Finally, disabled people in Brazil still suffer from violence, which is random and irrational, carried out with the express purpose of degrading, humiliating and stigmatizing them. Although it is punishable by law in Brazil, violence frequently occurs on the streets, in traffic jams and parking lots, when disabled people are most unprotected. Such violence in São Paulo has discouraged many physically impaired drivers from putting stickers with a handicap symbol on their car, because to do so makes them an easily identifiable target for attack. In general, those individuals whom the attackers perceive as fragile and slow to react, women, elderly and those with impairments are targeted in the traffic and on the streets.<sup>30</sup>

This brief overview of the different ways in which Brazil’s disabled people experience oppression has suggested just how frequently this group is victimized. While the forms and intensity of oppression vary with different kinds of impairment, Brazil’s Constitution and its

human rights policies are unlikely by themselves to eliminate these structural forms of social discrimination. What they can do perhaps is act as a continued catalyst for the development of new norms within the dominant Brazilian population; values built explicitly on calls for human dignity and human rights for all of the nation's citizens.

## **Summary**

This chapter has argued that prior to ratification of Brazil's democratic Constitution in 1988 and its incorporation of new rights assurances, assistencialism served as a rationale for such support as was provided to the poor and disabled. Rights have since become crucial in the governments' discourses on building full citizenship for both disabled and nondisabled Brazilians. The nation has undertaken numerous efforts and devised multiple plans since adoption of that constitution and the CRPD to secure the rights of disabled Brazilians to education, healthcare and employment. But to date, these initiatives have lacked transparency, accountability and vigorous inter-agency and inter-ministerial implementation. Moreover, as Young (1990) has argued, new laws and policies alone cannot eliminate the structural oppression that has for so long been imposed on millions of disabled Brazilians. While such is surely a necessary step, it is not sufficient and must be accompanied by changes in major economic, political and cultural institutions and the values underpinning them, if substantive social change is to occur.

The next chapter discusses how Brazil's national government has slowly incorporated the language of rights into its policies and what that has meant for the nation's implementation of the provisions of the UN Convention on the Rights of Persons with

Disabilities. I critically analyze how the Brazilian federal government has implemented the Convention to date by examining its policy priorities as presented in its First National Progress Report on the CRPD.

## **Chapter 5**

### **Brazil's Disability Policy Initiatives in Light of the UN Convention:**

#### **Emerging Justice Discourses**

Human rights claims represent relatively new, “values, concepts and strategies in the Brazilian language of rights” (Oliveira, 2002, p.57) and the same is true of disability rights more particularly. More broadly, until recently, disabled individuals were not explicitly recognized in binding instruments of international human rights law. Indeed, acknowledgment of disability as a fundamental human rights issue has developed slowly in the past three decades. Most international initiatives related to disability have been non-binding, or so-called ‘soft-laws’ and early instruments emphasized a welfare approach, in which the impaired were treated as objects or targets for welfare and charity (Kayess & French, 2008, p.14). That approach resulted in mostly passive citizenship for these individuals. Nonetheless, this strategy or stance was adopted, if any awareness was expressed at all, by many states in the world. Indeed, to this day, most UN member-states have no specific legislation concerning the disabled (Convenção, 2010, p.9). Fewer than 50 states around the world have anti-discrimination laws in place to protect the impaired and those nations are located mostly in the developed world (Mercer & Macdonald, 2007, p.548). These facts speak to the degree of invisibility and oppression that millions of disabled people worldwide have long experienced and continue to endure.

This chapter discusses the significance of the UN Convention and its implications for Brazil's related policy initiatives and analyzes what can be done to improve the nation's relevant institutions and practices. It explores the purport and portent of the 2006 United

Nations Convention on the Rights of Persons with Disabilities for Brazil's disabled citizens. The argument is comprised of three parts. First, I trace the evolution of the Convention as the culmination of a 30-year dialogue among the UN, governments and civil society organizations worldwide. As a legally binding instrument, the Convention enables disabled persons and interested civil society organizations to hold signatory states accountable for the protection and furtherance of disability rights in state (national) courts and politics. In this section, I also discuss the significance of the UNCRPD, some of the strengths and weaknesses of its provisions and the implementation challenges it poses for states. Second, I examine Brazil's implementation of the Convention to date. The Brazilian national government presented its policy priorities linked to the United Nations rights regime in its First National Progress Report on CRPD for 2008-2010 and these, in fact, were different from those offered by advocates of the disabled. Besides discussing the government's main concerns as those were outlined in its report to the UN, I also briefly discuss other Brazilian human rights-related initiatives. I focus especially on whether the nation has concentrated disproportionately on the realization of selected rights for disabled citizens while excluding others from consideration. Third, this chapter analyzes the strategic choices revealed by the nation's CRPD-related implementation initiatives in terms of the justice discourses that have emerged from those efforts.

### **The UN Convention on the Rights of Persons with Disabilities: Its Significance, Opportunities and Challenges**

The UN Convention was the first binding instrument in the long struggle of impaired individuals worldwide to secure protection and promotion of their human rights. The previous

disability-related regimes developed under the auspices of the UN were non-binding and had rather a medicalized emphasis, failing to recognize impairment as a part of human diversity (Kayess & French, 2008, p.16). The 1980s saw several attempts to garner international community acceptance of a human rights convention specifically aimed at this population. For example, the UN declared 1981 the “International Year of People with Disabilities,” helping to bring visibility to the issue. Subsequent United Nations adoption of the World Program of Action concerning Disabled Persons in 1982 and declaration by the world body of a Decade of Disabled Persons (1983-1992) also was aimed at sensitizing populations to the rights of these citizens.

Several UN-initiated disability-related declarations and treaties as well as international and regional efforts to protect the rights of the disabled population preceded the Convention’s adoption: the 1975 Declaration on the Rights of Disabled Persons; the 1991 Declaration of Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care; the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities; the 1994 Declaration of Salamanca concerning education; the 1999 Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities; and many others. The Convention reaffirmed the principles embraced in the Universal Declaration of Human Rights of 1948 and superseded that and other declarations and instruments of the UN and other institutions, in so far as disabled individuals were concerned (International Disability Alliance, 2008).

Lopes (2009) has detailed the efforts of civil society organizations internationally to press for a specific convention on disability rights because the existing international and

regional human rights norms and instruments were insufficient to address the issues concerning people with impairments appropriately. Participants in the March 2000 World NGO Summit on Disability in Beijing agreed to support the elaboration and adoption of a specific regime on disability rights and they sought to outline such an effort in the Beijing Declaration on Disabled Persons in the New Millennium. Ultimately, Mexico's 2001 campaign for a disability rights convention was successful in launching a UN effort to craft the instrument (Kayess & French, 2008, p.17). Part of Mexico's rationale for its initiative was the fact that disabled individuals, 80 percent of whom live in developing countries<sup>31</sup> and account for a significant share of the poor in those nations, were left out of the Millennium Development Goals formulated by the UN in 2001. As a result, there was a real possibility of this very large population being ignored entirely in global development efforts. One major implication of that oversight was broad recognition that many of the Millennium Development Goals could not, in fact, be fulfilled without addressing disability-related injustice in the developing world (Mercer & MacDonald, 2007).

An analysis conducted by the International Disability Alliance (IDA) of the particular areas in which the 2006 CRPD replaced previous United Nations disability-related declarations and actions as well as those of several regional organizations, "demonstrate[s] an evolution of the norms that have now found legal expression in the Convention on the Rights of Persons with Disabilities" (IDA, 2008, pp. 1-2).<sup>32</sup> Those changes illustrated the limitations in how previous efforts had defined rights and reflected an increasing level of public awareness of the issue as well as a shift from a medical model of disability toward a more social one in which disabled individuals are not considered "objects" of charity or of medical treatment, but instead, "subjects" with rights. The CRPD embraced the view that disabled

individuals were not “problems to be fixed,” but individuals with rights to “participate as active members of society and enjoy the full range of their (those) rights” (Ibid).

States and interested civil society organizations, national human rights institutions and inter-governmental organizations negotiated the CRPD, the first United Nations human rights treaty adopted in the 21<sup>st</sup> century, from 2002 to 2006. The General Assembly adopted the Convention on December 13, 2006 during its 61<sup>st</sup> session and subsequently opened the effort for signature by all states and by regional integration organizations at United Nations Headquarters in New York on March 30, 2007. Eighty-one states and the European Union became treaty signatories at the opening ceremony. This total was and remains the highest number of initial acceptances of a UN convention on its opening day in history.<sup>33</sup> Since its entry into force in May of 2008 for signatory states, CRPD has become the universal standard regarding human rights for the disabled. The Convention replaced previous instruments for the 153 signatory states and 113 state parties that have now ratified it.<sup>34</sup>

The CRPD identified the rights of disabled persons as well as the obligations of state parties to promote, protect and ensure those claims, while through its Optional Protocol it also allows for inquiry into grave or systematic violations of its provisions in specific states (UN 2006). Although, as noted above, the CRPD is not the first United Nations disability rights-related instrument, it is nonetheless the first such specific binding agreement in international human rights law. Indeed, some scholars have argued it constitutes, “the densest exposition of human rights by the UN to date” (Kayess & French, 2008, p.22). As of May 2012, the UN website reported that 113 states had ratified the CRPD and 65 had adopted its Optional Protocol. That is, to date, approximately one-third of the nations represented in discussions of

the CRPD have committed (to a degree) to impose international sanctions on offending nations when violations of the human rights of disabled individuals are reported.

The 2006 CRPD sought, “to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities,” covering key areas such as, “accessibility, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, and equality and non-discrimination” (UN, 2006). The fact that more than 150 states have signed the CRPD may be seen as symbolizing a change in thinking about disability from its consideration primarily as a social welfare issue to a human rights concern. When viewed as a social welfare matter, all parties generally conceived of disability as a question of medicine and health. In this conceptualization, physicians’ judgments concerning the nature and implications of a disabling condition has considerable bearing for such matters as an individual’s perceived ability to hold a job or to receive injury compensation. This perspective de facto treats millions of the disabled as passive citizens and consumers of state assistance. Conversely, disability conceived as a human rights concern acknowledges that societal barriers and prejudices are themselves disabling. As the Preamble of the CRPD observed, “disability is an evolving concept [...] that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN, 2006).

Activists and scholars continue to debate whether the Convention set out new human rights or simply affirmed their application to the disabled. I agree with Mégret (2008) that the answer to this question is more complex than a simple ‘yes’ or ‘no’ (p.498). While The UN argues that the CRPD did not create any new rights or entitlements, but rather clarified,

promoted, protected and assured their fulfillment by states,<sup>35</sup> one disability rights activist I interviewed argued that it did define a new right: namely, one to an accessible environment.<sup>36</sup> Some scholars believe the CRPD, “modified, transformed and added to traditional human rights concepts in key respects,” including a conferral of collective rights, including the right to research and development, awareness raising, social protection and poverty reduction and to international cooperation, including co-operation in international development programs (Kayess & French, 2008, p.32). Mégret (2008) has suggested CRPD represents “a very subtle mix of the old and the new,” which affirms, reformulates and extends the relationship between human rights and disability (p.498).

The CRPD endorsed rights scattered in other human rights treaties, arguing their appropriate application to disabled individuals or, put a bit differently, the Convention affirmed the “right to have rights” (Mégret, 2008, p.500). Among the affirmations contained in the Convention are: the right to life (Art.10), equal recognition before the law (Art.12), liberty and security of person (Art. 14), physical and mental integrity (Art.17), respect for home and the family (Art.23), education (Art.24), health (Art. 25), work and employment (Art.27), adequate standard of living and social protection (Art.28) and cultural life, recreation, leisure and sport (Art.30) (Mégret, 2008, p.499). Some of the rights were reformulated to take account of the particular needs and experiences of the disabled, such as retaining fertility equally with others (Art. 23), respect for the privacy of personal, health and rehabilitation information (Art. 22) and a number of others. In many instances as Mégret (2008) has observed, the CRPD, “fundamentally renew[ed] our understanding of what these rights mean and imply” (p.507).

Owing to the particular vulnerability of the disabled population, the Convention specified several rights in separate categories, such as “freedom from exploitation, violence and abuse” both inside and outside the home (Art.16), thereby extending protections into the family. Mégret (2008) has suggested such efforts together de facto constitute a right to participate in society and community (pp.508-509). Finally, CRPD comes close either to creating new rights or to formulating them afresh in the context of disability: personal mobility (Art.20) and accessibility (Art.9) and recognizing the legal capacity of disabled persons (Art.12). Taken as a group, Mégret (2008) has argued these provisions constitute a “legal culmination of the recognition of autonomy” (p.511). This scholar may be correct in that independence is crucial in reinforcing the capacity of this population to realize fully its rights in day-to-day living. Indeed, according to the Commissioner for Human Rights of the Council of Europe, “[I]t [the Convention] signal(s) [a] deeper understanding of equality.”<sup>37</sup> Inclusion of disabled people on equal terms into society and community matters would not likely occur without recognition of their autonomy. Acknowledging people’s independence also implies recognizing the inherent human worth of all, and promoting a normative ideal of equality, which is at the heart of both justice and democracy. However, this liberal notion incorporated by the CRPD may be problematic for some severely impaired individuals who cannot reason and judge for themselves, an issue I treat more fully below.

This fact points up a salient issue. At its heart, the Convention embodies a liberal framework of rights. While these principles are applicable and important for millions of people with impairments, those who are profoundly disabled are excluded from them and it is difficult to justify their inclusion solely on such foundations (Reinders, 2000, p.120). I point to the liberal nature of the CRPD because it has bearing, together with Brazil’s liberal

Constitution of 1988, discussed in Chapter 4, on the configuration of the conceptions of justice pressed by disability NGOs in Brazil. I examine those in Chapter 6.

**Criticisms.** Despite its historical importance to the disability rights movement around the world, the CRPD does suffer from concerns endemic to human rights treaties generally, namely, “the efficacy of monitoring devices, the sufficiency of content, and prioritization issues when State resources are limited” (Stein, 2007, p.94). Accordingly, the treaty has attracted a series of criticisms that I discuss below.

Kayess and French (2008), among other scholars, have criticized the structure and definitions incorporated in the CRPD. First, they point out the accord blends civil, political, economic, social and cultural rights, both within its overall structure and in its individual articles. That orientation seems to conflict with its stated aim (in Article 4) to distinguish between those rights subject to immediate realization (civil and political) and those only attainable over time (economic, social and cultural) (Kayess & French, 2008, p.33). In practice, this apparent disjunction may complicate implementation as well as reporting concerning progress in attaining Convention aims. In terms of CRPD enactment, isolated policies need to give place to multi-sectoral ones, in which the issue of justice for the disabled does not stand as a separate set of strategies, but is integrated into provisions regarding other socioeconomic issues, such as housing, transportation, city planning, education, tourism and leisure, etc. All of the disability advocacy activists I interviewed emphasized the need for multi-dimensional policies to bring together many governmental agencies and NGOs to advance specific issues toward broader goals. For example, making means of communication and information accessible to people with impairments contributes to their education, job

qualifications, political activity and overall quality of life. To this end, for example, the Ministry of Communications might partner with the Ministry of Education and Culture, Ministry of Labor and Ministry of Social Development and various NGOs with related interests to ensure that means of communication and information are accessible to Brazil's disabled citizens.

However, discerning how best to blend types of rights will not be a problem for implementation if the capabilities approach is adopted for policy design and implementation. It may take a combination of different sorts of rights for an individual with impairments to enjoy cultural life fully—accessible media, books, museums, staff and training to serve the population, accessible means of transportation and buildings designed to ensure access and personal mobility and assurance of an appropriate standard of living, etc. In practice, rights are interrelated in complex ways and it is inefficient and impractical to address their implementation on behalf of the disabled on an item-by-item basis, as the CRPD suggests.

Another major criticism of the Convention is that it conflates disability and impairment (Kayess & French, 2008, p.21). While the link between impairment and disability seems clear in the definition of 'persons with disabilities' in article 1 of the CRPD,<sup>38</sup> Kayess and French have suggested that in the remainder of the accord's text, the protection provided seems to be, "post-facto—only available to those persons with impairments who are already subject to discrimination and oppression, rather than those persons who may be at risk of it" (p.21). Disability rights activist Marta Russell has underscored this point by observing, "impairments are viewed as abnormalities and people who have them become devalued objects of the medical and social services establishment. Traditionally human rights have been

applied to disabled persons as objects of rehabilitation and prevention, not as subjects considered fully human with comprehensive rights of citizenship” (Russell, 2003, para.5). Her comment helps to illustrate the point that until recently, people with impairments were not even included in society. Instead, they were institutionalized and often not educated. Thus, people with impairments are consistently at risk of oppression in Brazil. Although privileged material conditions may alleviate some of the marginalization and powerlessness for some individuals with impairments, the conditions of structural oppression that disabled people endure as a group are deeply rooted in the society. Young’s (1990) account of oppression, discussed at the end of the previous chapter, helps the analyst understand the group oppression reproduced by major economic, political, and cultural institutions (p.41).

We may substitute the phrase ‘persons with impairments’ for ‘persons with disabilities’ and note the distortion to which Kayess and French pointed earlier. This may partially be an issue of priorities, as Stein has suggested, but there is a deeper epistemological question at play as well. The social model of disability significantly influenced the UNCRPD’s development (Kayess & French, 2008, p.7), and both the advantages and limitations of the approach were carried over into the Convention’s provisions. In the social model, disability is conceived as a kind of oppression from an inaccessible environment and discriminatory society. Thus, if the aim is to change oppressive social structures and attitudes, it indeed would make sense to protect all people with impairments, rather than only those already oppressed. Moreover, as noted in Chapter 2, one of the main criticisms of the social model is the dualism it establishes between impairment and disability, a situation that has spurred some scholars to call for linking ‘social’ (disability) and ‘non-social’ (impaired bodies), instead of posing them against each other. However, Stein (2007) suggests that the

CRPD was able to overcome the shortcomings of the social model by combining first, second and third generations of rights in its texts (p.93).<sup>39</sup> The Convention is doubtless crucial to bolstering Brazil's disability rights agenda, but activists should neither undervalue, nor overestimate its role, scope and potential contribution to securing human rights for the nation's disabled in the future (Kayess & French, 2008, p.34). It is worth recalling in establishing appropriate expectations, as some have cautioned, that the human rights agenda, "is not a comprehensive political program. It does not supply answers to many important political questions; rather, it leaves them to the democratic political process" (Goodhart, 2005, p.165).

Scholars have directed attention to other challenges to the Convention's implementation as well. First, a lack of meaningful enforcement mechanisms leaves realization of the CRPD's provisions up to each country and therefore to the vagaries of each nation's politics and commitment (Mercer & MacDonald, 2007, p.548). Beyond this concern, I would add that effective execution depends on the internal capacity of the states to devise and carry out appropriate policies as well as on the existence of a strong disability rights movement both to prod and to partner with the public and private sectors as needed. Stein (2007) has argued the effective monitoring of human rights treaties depends on a number of factors, including moral persuasion, political pressure and the ability of NGOs to increase issue awareness and salience (p.97).

As Lang (2009) has observed, many developing countries (including Brazil<sup>40</sup>) lack reliable and robust statistics on their populations with impairments, which bears on the issue of these governments' abilities to plan and implement appropriate services effectively (p.276).

Moreover, in the long-term, Lang sees this situation potentially resulting in “an inherent democratic deficit in upholding disability rights,” since obtaining basic services is indispensable for exercising other rights (Ibid). Moreover, on another level, the complexities of social policies imply the need for the establishment of policy networks that bring policy-makers and civil society organizations together to work jointly on policy formulation and implementation on behalf of the disabled, recognizing that the public sector alone is unlikely to do so successfully (Lang, 2009, p.272).

Second, the CRPD established a Committee on the Rights of Persons with Disabilities (Art.34), to which states periodically report their progress in implementing the treaty. The Committee, in turn, was empowered in the Convention not only to receive national reports, but also to comment on their implications for the progress of the population they aim to serve. While the government prepared the draft of Brazil’s first such report in the first half of 2011 and opened its text for public comment, the nation did not submit a final version to the UN until late May 2012. Consequently, the Committee has not yet been able formally to comment on Brazil’s progress in implementing the Convention.<sup>41</sup> This demonstrates the weak enforcement mechanisms available to the United Nations, at least in terms of reporting on nations’ implementation progress.<sup>42</sup>

To conclude, as the international community’s first legally binding international instrument, the Convention potentially could serve as a transformative force in the lives of the disabled worldwide. The CRPD helped an already growing social movement formalize and legitimate its aims and it put disability justice on many national agendas for the first time. However, the accord’s scope and potential in securing the human rights of the disabled in the

future should not be overestimated, and as Lang (2009) has warned, “[it] should not be seen as a panacea that will end discriminatory policies and practices, but rather will result in the emergence of a new set of challenges, some of which have not been foreseen” (p.267). As a negotiated international instrument, the CRPD necessarily blended a variety of perspectives, which resulted, according to some scholars, in inconsistency in adopted terminology and overall structure. In practice, this may complicate implementation as well as UN monitoring of efforts to attain the Convention’s aims, as a brief overview of the Brazilian situation will underscore below.

### **Patterns in CRPD Implementation in Brazil<sup>43</sup>**

When compared to many European countries, Brazil was slower in addressing the issue of disability rights (Araújo, 2001). The year of 1979 witnessed broad political mobilization of Brazilians with impairments and by 1984 the nation’s impaired population had its own organized movement (Lanna, 2010, p.33). The fact that the United Nations declared 1981 the “International Year of People with Disabilities” helped to bring national visibility to the issue. However, the Brazilian state did not assume formal responsibility for promoting and guaranteeing the rights of its disabled citizens until after its 2008 ratification of the 2006 United Nations Convention. While many government officials expected at the time that ratification would bring “immediate results” (Convenção, 2010, p.9), my interviews with several of Brazil’s disability movement leaders underscored the importance of the persistent hard work that had to occur over a long period to see significant change in social attitudes

toward the disabled and in their living conditions in Brazil. As one disability movement activist commented,

There will be need to be more time for action by social movement militancy [groups] to put this issue [disability rights] on the agenda of the state and society in general. There is a saying, ‘without action there is no right.’ We have a long way to walk in the defense of rights, of struggle, of denouncing, of militancy, to attain those changes, so that people with disabilities can live their lives with dignity.<sup>44</sup>

Before Brazil signed the Convention and its Optional Protocol, the Ministry of External Relations and other agencies sought to understand better the ramifications the initiative would have for State obligations and for the citizenship of the country’s disabled residents (Brazil, 2009). The President of Brazil sent the text of the Convention to the legislature in September 2007, strongly suggesting as he did so that the effort should be adopted with the status of a constitutional amendment. The nation formally ratified the international agreement in July 2008, and the Convention and its Optional protocol assumed the status of a Constitutional norm. No legislator voted against adoption and while the reasons for the lack of opposition were many, it is worth noting that the active efforts of the country’s civil society organizations to raise legislators’ awareness of the issue were one key reason for that outcome. Brazil delivered its ratification instrument to the UN in August 2008, becoming, respectively, the 34th (for CRPD) and the 20th (for Optional Protocol) state to do so.

Ratification of the Convention and its Optional Protocol had great significance for Brazil’s disability advocacy organizations. Two long-time activists of the disability rights

movement, each a leader in their respective organizations, described the Convention as a “victory of the movement”<sup>45</sup> and as a, “hallmark of a long process of discussions, agreements, advances, and intense reflections that happened during 4 years. This was possible thanks to the experience accumulated in 23 years [from 1979, when the movement began, to 2002, when the UN began its deliberations on the CRPD] by the national movement of struggle of people with disabilities.”<sup>46</sup> Another disability rights organization leader saw the Convention similarly as, “a form of observing the issue of social inclusion of people with disabilities, since historically there was an assistencialist approach to this population ... [which] strengthened the disability movement, equipping them with legal arguments in demanding rights and participation.”<sup>47</sup> The assistencialist approach was predicated on a, “charity for the afflicted” mindset and created dependency among its recipients while doing little to address the root causes of inequality they confronted. Also, the Convention fostered the possibility of dialogue between public sector representatives and leaders of civil society organizations in deconstructing the old, assistencialist logic and searching for new possibilities.<sup>48</sup>

Disability advocacy organizations have been active participants in Brazil’s deliberations concerning specific policies and actions to implement the aims of the Convention since its ratification. The groups involved do indeed see this as a special opportunity to press for change for those they seek to represent. As one advocacy NGO leader put it, “For changes in public policies to happen, the disability rights movement has to become a united pressure group, because governments deliver outcomes only under pressure.”<sup>49</sup> Many advocacy NGO leaders view political participation as essential in the struggle for economic, social and cultural rights and justice. As one disability rights activist observed in an interview, these leaders see political participation of the disabled as crucial if

they are to attain an enhanced quality of life as a group: “If we don’t have effective participation [in public spaces], it would be difficult to change the rules of the game. It’s hard to effectively promote changes to improve life conditions of people with disabilities when they are not present in decision-making processes.”<sup>50</sup> It is worth mentioning Inglehart and Welzel’s (2005) argument here, referenced in Chapter 2, that in order for disabled citizens to attain effective political participation, the state and society at large must first create social and economic conditions sufficient to sustain this population’s participation and protesting capacities.

Brazil’s activists appear to view political participation as a crucial element of a more fulsome citizenship for disabled individuals. In their view, public policy aimed at CRPD implementation must also reflect this priority. Nonetheless, the Brazilian national government’s policy priorities were presented in its draft National progress report on the Convention and these, in fact, were different from those offered by advocates, as discussed below. Before outlining the government’s main concerns, it is important to understand the Report’s character and context.

Two years after ratification, the UN, as part of a periodic monitoring provision, asked the Brazilian government to provide a progress report detailing its actions to implement the CRPD. In the spring of 2011, the nation’s government published a draft report for 2008-2010 concerning Convention implementation progress and invited civil society organization representatives and disabled citizens to contribute documented evidence and suggestions that would be analyzed and possibly integrated into the final national report to the UN. The nation submitted its consolidated final report to the world body in mid-2012, a year after the first

draft was publicized, but its contents were not released to the public. For that reason, my analysis has drawn on the draft National Report, first presented in April 2011.<sup>51</sup>

The Brazilian government divided its National Report concerning Convention implementation into two parts: General and Specific. The General Report reviewed social justice issues, policies and the agencies / bodies responsible for addressing them. The Specific Report was organized in accordance with the CRPD's articles, detailing laws and policies enacted and programmatic actions implemented for each. Mégret (2008) has compiled a helpful listing of measures that states should adopt to ensure that the rights articulated in the Convention are effectively met. These include:

- Adopting or repealing relevant laws
  - Mainstreaming concern for disability rights
  - Establishing public awareness campaign(s)
  - Building and/or adapting targeted infrastructures
  - Training specialized personnel and employing individuals to oversee implementation efforts, to provide specific services, etc.
  - Providing support and assistance as required by the Convention's provisions
  - Consulting with organizations representing the interests of the disabled population
- (p.506).

The draft National Report argued that the government had taken steps to address all of these categories of action, but it offered little idea of which were accorded priority and why, or what the outcomes of state implementation efforts to date had been. That is, in general, the

National Report did not provide preliminary results of adopted policy actions, including increased access for the disabled to education, healthcare, social security and employment. For instance, when referencing policy actions targeting equal rights promotion for disabled women (Art.6 of the Specific Report), several existing indicators could have been used to provide general context, but they were not employed.<sup>52</sup> Measuring gaps in political participation, access to technology, healthcare, transportation, education, earning capacity, etc., among the disabled and nondisabled, among women and men, white and non-white, urban and rural, could yield many useful insights that could help to gauge the efficacy of adopted public policies across the nation (for details about the National Survey on the Inclusion Gap in the US, see Stroman, 2003, pp.112-113), but the Report did not offer this sort of data either. Nevertheless, for Brazil to develop truly inclusive policies, its public leaders will need to identify these gaps and create and track programmatic and policy efforts to address them. That step has not yet occurred in the nation.

The authors of the draft Specific Report analyzed Article 4 implementation of the CRPD by distinguishing among short, medium and long-term strategies devised to address it, instead of immediate and progressive implementation of the rights as required by the Convention. This subtle distinction may generate confusion among those interested in following Brazil's efforts to realize the treaty's aims, as I show later in this section.

The nation's short-term strategy for attaining CRPD goals focused on three main elements: first, developing policies for basic healthcare for the impaired; second, effective implementation of norms to increase the access of the disabled to public services and the job market and third, adopting measures to ensure impaired individuals' access to media and

means of communication. While the authors of the CRPD assumed these economic, social and cultural rights were likely to be secured progressively over time, the Brazilian government has nonetheless sought urgently to ensure them in the short term, which carries a potential to generate some policy inconsistencies. For example, to foster the employability of the disabled, the government chose to focus on providing vocational training for the population. However, employment-related training cannot substitute for the provision of a solid educational foundation, on which the government decided to focus only in the medium run. It appears to make more sense to combine both educational and vocational efforts in a unified short-term strategy.

While the Specific Report offered great detail concerning the various agencies and programs in place to promote the employability of disabled youth and adults, it said nothing about specific legislation or actions taken to promote entrepreneurship among members of this public. Brazil's laws, policies and social norms do not support such efforts by the disabled. Nonetheless, encouraging entrepreneurship seems to be one feasible alternative to help lower the disabled population's traditionally high unemployment rate and to help such citizens overcome social prejudice and achieve economic independence.

The nation's medium-term policy implementation strategy entails the consolidation of inclusive education policies for the disabled population<sup>53</sup> as well as development of programs that seek to remove barriers that hinder impaired citizens from fully participating in daily social and political life. The CRPD called for enhanced political participation by the disabled as a key means to guarantee their human and civil rights. Advocacy NGO leaders who work with impaired individuals daily agree and consider promoting political participation as the

foundation on which to build other rights for disabled citizens. Thus, they contend that delaying removal of barriers that hinder their political engagement may delay or even deny full citizenship for the disabled. Furthermore, postponing efforts to ensure education for impaired people is likely only to perpetuate the social injustice these citizens already experience. One consequence of this is poor employment opportunities and self-employment prospects for the disabled due to lack of education. The nation indicated in its draft UN Report that it will address this imperative only in the longer run.

Another major consequence of this choice is that it looks set to hinder the development of disability studies scholarship in Brazil by reducing the participation of the impaired in such efforts. In this view, disability studies, “is a means to think critically about disability, a juncture that can serve both academic discourse and social change” (Linton, 1998a, p.1). Disability scholarship may also inform the debates around CRPD implementation, offering critical insights and reflection on the policies and programs adopted. This is not to say, as Shakespeare has pointed out, that just because someone has a disability means they can offer insights into the lives and experiences of all disabled people as a class, since impairments and experiences are so diverse (2006, p.195). However, other scholars, including Linton (1998a, 1998b) and Oliver (1999, pp.183-184), have questioned the benefit and validity of research in this domain when not informed by disabled people’s perspectives. Indeed, if the inquiry is focused on the needs and costs of service provision for the impaired, and not on their political and social rights, their integration and inclusion into the wider citizenry is unlikely to be sustained.

The Specific portion of Brazil's draft Report left the conception of systems of information and identification of indicators that would measure the effects of enacted policies, as long-term goals (Art.4c), a stance that implies the effects of short-and medium-term (Art.4a and 4b) policy actions to implement the Convention will not likely be measured, tracked and reported. CRPD Article 31 focuses on Statistics and Data Collection regarding the disabled population, but it does not specifically require its immediate implementation, thus allowing signatory parties discretion to interpret its relative priority. Nonetheless, Article 31 does mention that research information should be used to report CRPD implementation progress. I presume that attention to this obligation would be better taken in the short-term rather than the long-term, but the lack of clarity in the text gives room to rank such actions differently. In any case, it appears that vigorous conduct and dissemination of research on the dimensions of disability injustice likely would not only make Brazilian federal, state and municipal policies more effective, but also empower the disabled in their struggle for justice.

Moreover, such inquiry would help put disability justice on the nation's scholarly research agenda, which has not occurred to any degree to date (Lanna, 2010, p.12). By highlighting and sponsoring inquiry concerning disability and justice, the state could not only promote disability rights and potentially develop more effective policies, but possibly help to prompt a broader change in attitudes toward the disabled in the culture. Changing social values and relationships institutionalized in informal patterns of everyday life may be beyond the capacity of statutory mandates (Scotch, 2009, p.180) and partnering with many stakeholders in this process to realize the findings of research may help to advance such efforts.

In conclusion, Brazil's implementation of the CRPD is likely to be a complex and long-term effort 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. The nation has incorporated disability rights into its larger national human rights plans and policies, whose success ultimately will rest on developing an inclusive attitude in the broader population. However, the effectiveness of these actions will depend largely on the accountability and evaluative mechanisms built into their implementation. Measuring and disseminating the outcomes of enacted efforts and employing that knowledge to improve policies will help realize the rights of the disabled. The state actors responsible for promotion of disability rights should also engage more actively with the experiences brought to the table by the NGOs that work with the impaired on a daily basis, as well as with the disabled themselves, as their insights and lessons learned could help structure the nation's policies in a more realistic and manageable way, instead of, as now appears to be the case, an effort to identify quick fixes (as for example, valorizing vocational training instead of investing in education from early childhood on).

### **Implications of Human Rights Policies for Justice and Democracy**

This section analyzes the implications of recent human rights policies for Brazilian democracy and justice. I argue that as now conceived by the nation's public leaders, such efforts are of limited benefit to democracy, as they do not address the deeper injustices confronting the disabled by avoiding dealing with several oppressive constraints operative in their lives.

Brazil's draft National Progress Report builds on the nation's 3<sup>rd</sup> Human Rights National Plan, or HRNP-3, enacted in 2009. Several points may be made concerning this effort. One of this Plan's main goals was to strengthen participatory democracy through human rights policy implementation. That argument establishes a positive relationship between promoting democracy and human rights in the document. However, it does not make clear where human rights fit in enhancing democracy in Brazil. With persisting oppressive public attitudes and norms, implementing human rights policies formally will have a limited impact on realizing a more vigorous Brazilian democracy in practice. The nation's institutions and practices still permit very large governance roles for landed elites, who are often able to stymie efforts to create more participatory forms of democracy (Montero, 2011, p.116-117). Long established clientelist practices and flawed political institutions that underrepresent women and minorities in politics and policy-making still characterize the nation's culture and politics (Montero, 2011, p.117). Disabled citizens' interests and needs are not always well represented in politics and Brazil's current institutions do not encourage these citizens' active participation, which, in any case, becomes difficult to attain when the basic needs of many in the population are not met. These issues are not reflected in the country's revised and updated human rights policies and these weaknesses will make it more difficult for Brazil to realize full human and civil rights for the disabled as well as a more vigorous participatory democracy generally.

Brazil's current human rights policies do acknowledge population diversity in an effort to promote equality. The HRNP-3, for example, contains guidelines that encompass multiple dimensions of diversity in Brazilian society (age, race, gender, impairment, sexual orientation, ethnicity, etc.). The plan calls on all interested parties to recognize these groups in

efforts to construct a more egalitarian society. Acknowledging the nation's diversity while promoting and protecting universal human rights is a significant step. However, without changes in the nation's major economic, political and cultural institutions to boost the representation of women and marginalized groups, their public roles will remain limited. Highlighting this reality suggests how important it is to avoid reducing democratic politics to human rights politics and to eschew embracing the mistaken view that formal adoption of a treaty or law ensures its effective implementation or the realization of its aims in democratic politics.

The HRNP-3 highlights civic education and public awareness as important elements in attaining several of its central goals. Mainstreaming disability rights (together with women's rights, gay rights, etc.) is part of a series of measures the Brazilian government has adopted to promote equality and non-discrimination of diverse disadvantaged social groups. Since, as Oliveira (2002) has pointed out, the great majority of the nation's citizens exhibit low levels of political literacy and information about human rights, actively promoting the language of rights in policy may potentially strengthen the citizenry's (and nation's) "democratic ethos" (p.70). However, Oliveira (2002) has also cautioned that civic education has been problematic in Brazil due, in major part, to low levels of formal education in the general population (pp.66-67). She reports, as noted above, that 66 percent of Brazilians have fewer than four years of schooling, which is hardly sufficient to understand the language of official documents or complex human rights obligations (Ibid, p.67). Moreover, socioeconomic and regional inequalities and discrimination persistently exclude large portions of the population from ongoing civic education efforts.

Human rights education and public awareness-raising efforts (Guidelines 3 & 5 of Human Rights National Plan 3) are crucial in creating and reinforcing a culture of human rights in Brazilian society (Brazil, 2009b). Education was incorporated into the first HRNP in 1996 and its second version in 2002 in the hope of creating a permanent national campaign to improve society's understanding and respect for human rights. However, it is difficult to measure how successful these measures have been since there is no research available concerning their reach or efficacy and the government has not evaluated the outputs or outcomes of its formal policy either. Moreover, as mentioned earlier, postponing guaranteeing the right to education of Brazil's disabled children and youth will limit their ability to benefit from human rights education and inclusive participation. That scenario in turn is likely to continue to hinder construction of a culture of human rights in the nation.

The Convention as well as already enacted human rights policies would probably benefit Brazil's democracy-building efforts if fully implemented. However, structural constraints may limit the Convention's policy outcomes. After studying the documents, one can see that Brazil's policies seek to create and sustain a culture respectful of human rights, but in an individualistic sense. Iris Young's (1990) account of structural oppression discussed in Chapter 4 is helpful in understanding the experience of the country's disabled people as an oppressed group. As mentioned earlier, oppression is not a result of a few people's choices, but rather the everyday practices and unconscious assumptions and attitudes of liberal society that will not be eliminated by passing new laws and policies. In Young's account, oppression inhibits people's ability to develop and exercise their capacities. In Brazil's case, social and cultural contexts and processes leave the disabled marginalized, powerless, culturally dominated and violated.

While the intensity of oppression is likely to vary among different individuals with different types and levels of impairment, Brazil's individualistic model of rights, espoused in its Constitution and its human rights policies, seems likely to exert only a limited effect on the structural oppression that these individuals experience as a group. This is so because the approach implicitly assumes human rights are based on the protection of individual rights and these are very difficult for the disabled to realize in a culture that has not valued or even recognized them until very recently. In the next chapter, I examine the conceptions of justice embraced by leaders of the disability NGOs that operate within and, knowingly or not, often act to reproduce, this liberal framework of rights by investigating the claims they advance concerning citizenship and responsibility for justice for the disabled. I argue that Brazil's embrace of liberalism's tenets makes it far more difficult than it otherwise would be to justify and legitimize the nation's inclusion of its citizens with severe or profound impairments.

### **Summary**

This chapter has examined Brazil's experience following its adoption of the UN Convention on the Rights of Persons with Disabilities. The treaty potentially could help to transform the lives of the disabled in Brazil and worldwide. Indeed, in Brazil, the CRPD has helped an already growing social movement formalize and legitimate its aims and to place disability justice on the national political agenda. However, as a negotiated international instrument, the treaty blended a variety of values and perspectives that resulted in an inconsistency in adopted terminology and overall structure. In practice, this internal contradiction may complicate implementing the accord as well as make reporting concerning progress in attaining its aims more difficult, as this brief review of the Brazilian situation has underscored. The state has

incorporated disability rights into its larger national human rights plans and policies, an important inclusive step. However, the effectiveness of these actions will depend largely on the accountability and evaluative mechanisms built into their implementation and the evidence thus far is not hopeful. Moreover, the nation's relatively new human rights policies will be of limited benefit to the development of its democracy if they do not prompt effective steps to address the deeper injustices confronting the disabled that inhere in prevailing social and cultural attitudes.

## **Chapter 6**

### **Justice Discourses of disability NGOs**

Disability rights NGOs were fundamental in both negotiating the content of the CRPD at the UN and in efforts to advance the rights of disabled people in Brazil more generally. Many of these organizations have sought to equip the impaired with knowledge and strategies aimed at advancing their rights claims with Brazil's government. Under pressure from these institutions, the nation's regime has sought to devise appropriate policies to implement the Convention since formally adopting it. In what follows, I explore the justice discourses and claims advanced by Brazil's disability NGOs as they have sought to influence CRPD implementation. I seek to analyze their current efforts to secure social and political change for the nation's disabled citizens. Selecting the major arguments concerning justice from NGO reports, interviews with a sample of their leaders and their websites, I appraise the ways these efforts are affecting the citizenship claims of the disabled population of Brazil.

This chapter is organized into three parts. I first provide a brief overview of the evolution and current status of Brazil's disability NGOs. It is important to understand the context in which these organizations developed during the past few decades in order to understand fully their current advocacy and direct service roles. Second, I explore the conceptions of justice for the disabled advanced by these service and advocacy NGOs. The pursuit of full citizenship is implicit or explicit in the mission statements of many of these organizations, and their understanding of what such might entail has shaped their advocacy claims and strategies. Finally, I analyze the implications of liberal conceptions of justice and citizenship in the chapter's third section, since these both grant rights and require the exercise

of specific responsibilities. These claims, particularly, pose a challenge for all of the nation's severely or profoundly impaired individuals.

### **Overview of Disability NGOs in Brazil<sup>54</sup>**

Brazil's disability NGOs evidence a variety of different structures and strategies and these operate at multiple scales: local, regional, national and international. Local-level NGOs include:

- Advocacy organizations that work to guarantee the rights of the disabled,
- Local self-help groups, and
- Service providing organizations.

Regional and national-level NGOs include coalitions and groups established as the disability rights movement grew and unified advocacy efforts were perceived to be necessary by those involved if their efforts were to prove efficacious. Finally, international nongovernmental organizations, or INGOs, have been important actors in political agenda setting and mobilization efforts and successfully sharing the experiences of specific groups and populations across borders.

The Brazilian state established two schools for individuals with impairments during the 19<sup>th</sup> century, the first of their kind in Latin America: The Imperial Institute for Blind Boys and The Imperial Institute for the Deaf. However, these state-supported organizations were very small and as a result, civil society groups organized their own institutions to serve these populations in the 20<sup>th</sup> century. These private nonprofit organizations included, among others,

Societies Pestalozzi and the Association of Parents and Friends of the Exceptionals (APAEs) for those with intellectual impairments. The first organizations created and administered by people with impairments began to emerge in Brazil in the mid-20<sup>th</sup> century (Lanna, 2010, p.28). Initially, their motivation was securing solidarity among those with various impairments for mutual support and survival. These NGOs did not have political aspirations. They had no headquarters, by-laws, and few other formal structural elements, but the convivial experiences they helped create nonetheless framed many important debates about common issues and challenges confronting the populations they served (Lanna, 2010, p.33).

The disability rights movement that emerged in the late 1970s in Brazil sought to position people with impairments as political agents (Lanna, 2010, pp.12-13). The First National Assembly of the Entities of Persons with Disabilities took place in Brasilia in 1980 with the purpose of creating a single federation among existing entities. As matters evolved, the conference's organizers were vitally concerned with ensuring the participation of militants with impairments, resulting in the exclusion of those without impairments from decision-making processes and from the planned federation (Ibid, p.39). This step began a movement to distinguish organizations *of* persons with disabilities from those *for* persons with disabilities, a dichotomy in NGO advocacy organizations that persists in Brazil today. However, as one long-time rights activist observed in an interview, the disabilities movement in Brazil has some leaders within it with and without impairments who evidence paternalistic and assistencialist attitudes to those they represent.<sup>55</sup> I discuss this long-term tension more fully below when analyzing the rhetoric concerning constitutes legitimate representation of the nation's population with impairments.

This brief overview suggests the complexities endemic to current efforts to secure social and political change for Brazil's disabled. Considered in a somewhat simplified way, the mission statements of more than a dozen disability organizations I reviewed highlight social inclusion of people with various impairments as their central purpose.<sup>56</sup> Their institutional reports and websites all emphasize principles of autonomy, equality, dignity and respect as crucial elements of their projects and efforts. As I have noted, some of these entities have turned to advocacy strategies in their efforts to secure the human rights of the disabled and have sought to empower that population to take charge and voice their concerns in the political process. Others have sought to provide needed services when the state has not done so. These have included rehabilitation and neuro-rehabilitation, educational and vocational training services.

Nonetheless, and despite an apparent uniformity of purpose, at least at the macro level, analysis of ongoing NGO efforts to empower Brazil's disabled population reveals a number of tensions at play. These broadly revolve around financial and methodological issues. First, the great majority of these organizations struggle to ensure fiscal sustainability. While the mission statements of many stress their central interest in advancing the rights of the disabled; in practice, their survival often becomes their primary concern, and assuring the rights of those they nominally serve becomes a secondary matter.<sup>57</sup> Worries about financial sustainability also may lead some organizations to trade their expertise and independence for securing contracts with federal and local governments or corporations. For example, when a company needs to conform to quota obligations under Brazilian law (a compulsory percentage of employees with impairments), it usually approaches several NGOs to train impaired individuals for future placement in the company. However, the firm may stipulate the kinds of

impairments it prefers, candidates' age and other characteristics as well as the content of the development process, if ongoing or already existing efforts do not appear to serve its goals. Cost-benefit is a guiding principle for both public and private contracts of this sort and some NGOs may be in such need of resources that they agree to this restrictive logic, even if at times it implies certain discrimination against their purported primary stakeholders and violation of their organizational principles and values. If a certain kind of impairment, for example an intellectual disability, is expensive to address, civil society organizations may often choose to provide services for populations with other impairments instead, as one of my interviewees noted.<sup>58</sup>

A second tension evident in NGO efforts to advocate on behalf of the disabled in Brazil is related to the previous one and concerns competition among these entities for resources and salience. The struggle for financial resources and to secure survival has created a significant barrier to collaboration among these organizations. While some cooperative efforts do exist, in general two-way organizational practices are hard to sustain, as one disability rights activist mentioned in an interview with me.<sup>59</sup> Indeed, it is not far-fetched to suggest that the struggle for resources among Brazil's disability NGOs has come to resemble the strong competition evidenced among for-profit companies in the country.<sup>60</sup>

The third observed tension concerns legitimacy of representation, or who may rightfully speak on behalf of disabled people. This issue was first raised when the Brazilian disability movement formed in the late 1970s. All interested NGOs claim to represent disabled people in one way or another, but a review of these organizations' reports<sup>61</sup> and websites<sup>62</sup> and interviews with their leaders revealed that several notions of political

representation are at play among them. I was able to identify perspectives on legitimacy related to identity, service and mediation in the rhetoric of a sample of NGOs serving the disabled.

Houtzager and Lavallo (2010) have conducted a study of a broader sample of more than 200 civil society organizations in São Paulo that worked with the urban poor and my findings are similar to theirs with respect to the issues of claiming representativeness and legitimacy to speak on behalf of the people the organizations serve. For their part, militant advocacy organizations formed by activists with impairments see themselves as the only legitimate voice of the disabled, thus eliminating the difference between the represented and the representative organization. However, only a small minority of Houtzager and Lavallo's 229 participating civil society organizations, less than 5 percent, in fact, articulated identity-based notions of representation. Only this very small percentage advocated essentialism or the substantive similarity of those representing and the represented to ensure that, "the interests of the latter are known by the former and will be faithfully represented because of their shared interests" (Houtzager & Lavallo, 2010, p.19). My search also revealed that service-providing NGOs claim representativeness on the basis of providing services and improving the quality of life of those they serve. These NGOs have attracted criticism that their efforts bring too little difference to the lives of those they purport to represent, although what might constitute "adequacy" is unclear (Houtzager & Lavallo, 2010, p.22). While an important share of advocacy NGOs also makes the service argument (Ibid), some service NGOs in São Paulo do press demands for government action and also participate in collective advocacy, although it is not their core activity (Lavallo, Acharya & Houtzager, 2005, p.956), which suggests that

service NGOs can be as actively engaged in agenda-setting efforts as their disability rights advocacy peers and that differences in activities are not clearly established.

However, militant advocates view service organizations as outside of the movement, since disabled people do not typically control them and they are not generally involved in the political process. But, as just noted, these assumptions are not accurate for all such organizations. For example, Fundação Dorina Nowill produces and distributes books in Braille and offers audio and digitally accessible texts directly to the visually impaired and to almost 2,000 schools and libraries throughout Brazil.<sup>63</sup> These efforts involve the organization indirectly in the political process. Similarly, the NGO Laramara provides training to the visually impaired so that they can ride public transportation, attend schools and churches and go to work.<sup>64</sup> The NGO also supplements public education efforts on behalf of children, youth and adults with visual impairments. Several organizations—such as Associação Brasileira de Ostimizados (ABRASO), or Brazilian Association of People with Ostomy; Associação Para Valorização e Promoção de Excepcionais (AVAPE), or Association for Appreciation and Promotion of the Exceptionals and Organização Nacional de Cegos do Brasil (ONCB), or National Organization of the Blind of Brazil—are organized in local chapters through which they participate in advocacy and execute their programs. All three of these NGOs promote the full development of their target populations and seek to raise social and governmental awareness of specific disability-related concerns through the network of their member organizations. ABRASO unites associations, clubs and centers nationally in defense of the citizenship rights of people with various sorts of ostomies, through their political organization, participation in conferences and international representation.<sup>65</sup> AVAPE provides outpatient clinics and related medical services, development of social coexistence skills and

professional rehabilitation and training for the disabled, in addition to job market placement.<sup>66</sup> Finally, ONCB promotes and participates in the development of public policies on behalf of people with visual impairments to ensure the full realization of their rights.<sup>67</sup> These organizations are hardly apolitical, because providing accessible books, supplementing education and enhancing the autonomy of individuals with various impairments are potentially innately empowering.

Freire (1973) has defined agency as the capacity to create and re-create one's reality. Humans integrate themselves into specific contexts, a process that not only involves adaptation to their perceived reality, but also implies a critical capacity to transform their environments through their own choices (Freire, 1973, p.4). In short, some service-providing NGOs offer opportunities that have deep political impacts for disabled individuals. It is simply not fair, nor accurate, to tar the entire universe of these organizations with the same critical brush.

Another notion of representation I identified in the NGO reports I examined was mediation. This occurs when these organizations help connect the often politically excluded population of the disabled to the state. That is, these organizations open channels to the government for the claims of the impaired who would otherwise lack such access (Houtzager & Lavalle, 2010, p.21). One example of an NGO pursuing a mediation legitimization strategy is Instituto Brasileiro dos Direitos da Pessoa com Deficiência (IBDD), or Brazilian Institute for the Rights of Persons with Disability, which has sought to work through the courts to protect and advance the rights of the disabled population in Rio de Janeiro for more than a decade. One example of IBDD's efforts is the case of a Brazilian man with a physical

impairment in Nova Iguaçu, Rio de Janeiro state, who needed a wheelchair. The state had not previously distributed wheelchairs to needy citizens in Nova Iguaçu and IBDD took a case to court to gain that support and won, in the name of the citizen, who had just such a need.<sup>68</sup> This and many other similar examples suggest that the basic needs of the population with impairments are not yet fully on the nation's public policy agenda.<sup>69</sup>

A fourth tension implicit in disability NGO efforts is their diverse understanding of what constitutes citizenship for the impaired individuals they seek to serve. I will discuss different notions of citizenship and what they entail for different organizations in the next section, in which I analyze disability NGO justice claims.

In sum, Brazil's disability rights organizations come in many varieties, depending on who is pressing claims, how they are doing so, what purposes they see themselves pursuing and the outcomes of their political efforts (Stroman, 2003, p.46). While their initiatives and projects are uniformly well-intended and focused on securing equal rights, dignity and respect for the disabled population they serve, in practice the efficacy of these organizations is limited by a series of tensions or challenges they all confront. Struggles for financial sustainability, competition for salience and resources, continuing controversy concerning the legitimacy of alternate representation strategies and diverse understandings of citizenship (the attainment of which, for the disabled, many have nonetheless established as a central purpose in their mission statements) all affect the outcomes of their advocacy efforts. I explore the justice claims of disability NGOs and how they are reflected in different understandings of citizenship next.

## **Conceptions of Justice Embraced by Brazilian Disability NGOs**

This section examines understandings of justice articulated in the discourses of disability NGOs. I traced these notions by investigating the justice claims these organizations advance on behalf of the disabled. I identified two sets of themes in these demands: a diverse understanding of citizenship and a sense of responsibility to secure a measure of justice for the disabled.

The injustices experienced by Brazil's disabled citizens every day motivate disability NGOs in their struggle to attain better life opportunities and fuller rights for the population they seek to serve. As mentioned in Chapter 4, the nation's 2010 Census once again confirmed that the disabled experience inequalities compared to the nondisabled in educational, employment and earnings opportunities. The disability NGOs all appear to operate on the assumption that if the rights of the disabled are guaranteed and their responsibilities appropriately allocated, their full citizenship will be secured and equality and justice achieved across the broader population. However, as I have noted, these assumptions apply only to intellectually unimpaired and responsible parties, since liberal citizenship grants rights and requires exercise of certain responsibilities on that basis. This poses challenges for efforts to attain legal, political and social equality and justice for those with severe or profound cognitive impairments.

The following quotations from two disability advocacy NGO leaders illustrate how they view the population they represent:

This public is still very invisible due to the process of social exclusion that they have been facing. Today, gradually, these people have begun to undertake public careers

occupy space in public careers, in politics, universities, but their effective participation is still very small.<sup>70</sup>

Because for a long time others spoke for them, today people with disability need this exercise of citizen participation, of this learning possibility. [...] We need to work in fact with the premise *nothing about us without us*, which is a very strong premise of the international movement of people with disabilities.<sup>71</sup>

These statements imply the invisibility and powerlessness of Brazil's disabled population, whose potential and experiences are hidden behind Census statistics. But they also suggest positive possibilities for the impaired. The leadership and staff of these NGOs appear to understand the view articulated by Wilson and Lewiecki-Wilson (2001) that they need to work to transform the negative legacy of disability and impairment in Brazil's culture in order to promote active social change and additional opportunities for the disabled (p.7).

NGOs' efforts to improve possibilities and rights for this population include promoting full citizenship for the disabled through increased access to appropriate education, culture, employment and sports, raising awareness about their rights, and providing legal advice /services. A few examples of such organizations follow. Associações de Pais e Amigos dos Excepcionais (APAE), or Associations of Parents and Friends of the Exceptionals, seeks to promote social inclusion of intellectually impaired people through arts, education, sports, vocational training, family support and rights protection, according to its website.<sup>72</sup> Another example is a regional organization Vida Brasil, or Life Brazil, which for 15 years has been working in the Northeastern region of Brazil, in Ceará and Bahia. Its focus is on human rights

and citizenship education among vulnerable population, including disabled persons. The organization's mission is to appreciate and strengthen marginalized and socially excluded individuals and groups through education and participation, to build a sustainable, inclusive and democratic society.<sup>73</sup>

RIADIS, a Latin American Network of Non-Governmental Organizations of People with Disabilities and Their Families, is a made up of organizations from 19 countries in Latin America and the Caribbean. As its website states, "RIADIS works to promote and protect the rights of people with disabilities in Latin America and the Caribbean, promoting the values of non-discrimination and inclusive development based on improving the quality of life and social inclusion of persons with disabilities and their families."<sup>74</sup> One recent RIADIS initiative is the Latin American Observatory on the Rights of Persons with Disabilities, which serves as a virtual tool for the exchange and dissemination of information, resources and best practices. The Observatory's aim is to provide technical, political and creative resources for capacity building in developing actions for the promotion of disability rights, as well as to serve as an instrument for monitoring CRPD implementation in the Caribbean and Latin America .

All of the NGO leaders with whom I spoke saw education as a fundamental right and many of their organizations offer their expertise to train teachers and school administrators and to design/prepare relevant school materials. With limited time and financial resources these NGOs must constantly innovate, as one disability NGO leader told me,<sup>75</sup> and sometimes undertake new tasks not previously within their province. An example of this, according to another interviewee, was several cases in São Paulo in which children with intellectual impairments were denied access to education by not being permitted to matriculate in their

local public schools. This individual's NGO devised a strategy to pressure the Secretary of Education to intervene to remedy the situation.<sup>76</sup>

Apart from flagrant discrimination of the sort practiced in São Paulo in the schools in the example just above, Brazil's disabled also confront a structural challenge to their inclusion in society: the nation's propensity to link citizenship to productivity. This assumption implies that if a person cannot be economically useful, he or she is not worthy of citizenship, a particularly pernicious idea for disabled citizens. To address this concern, interested NGOs cooperate with businesses to train and help formally employ adults with impairments. These efforts are doubtless important as a part of longer-term initiatives to address the economic injustice that many disabled citizens continue to experience. The process of economic empowerment and including the impaired more fully in the job market, where appropriate, will take some time and much more effort. Meanwhile, a recent survey conducted by the *i.Social* consultant group suggested that adults with impairments still have few opportunities in the job market and that employers' focus is more on conforming to legal quotas of impaired employees than on their economic empowerment.<sup>77</sup>

The discourse of what might be dubbed the "cost-benefit" conception of citizenship thus still trumps true membership of the disabled in Brazilian society. Rioux and Valentine (2006) have proposed expanding the landscape of citizenship to include disabled individuals' experiences so as to legitimate their presence as relevant political actors (p.55). The pressure from disability rights NGOs and from international agreements, including the UN Convention on the Rights of Persons with Disabilities, has persuaded many governments to embrace the equality of rights of citizens with disabilities and to advance anti-discriminatory protection to the population (Rioux & Valentine, 2006, pp.60-61). However, as one advocacy NGO leader

put it, for changes in public policies to happen, the disability rights movement has to become a still more united group, because governments deliver outcomes only under political pressure.<sup>78</sup>

The diverse understandings of citizenship discussed above are related to the allocation of responsibility among social actors for ensuring justice for disabled Brazilians. In the discourse on responsibility for justice, I was able to identify three responsible parties or agents—the state, NGOs and the disabled themselves. In interviews and in their written materials, NGO leaders argued that the state is responsible for providing services to its population with impairments, including rehabilitation, healthcare, social assistance, education, vocational training and many others. As one disability movement activist observed in an interview with me: “The more combative organizations understand that service provision is the obligation of the state, and that no organization without resources and without adequate conditions can substitute for the state in a satisfactory manner.”<sup>79</sup> Arguments like this have created a fault line among the disability NGOs since some militant organizations have come to contend that service provision by civil society entities diminishes the likelihood the state will accept what they understand to be its proper responsibility for such efforts.

Nonetheless, as I argued above, many so-called “service” NGOs do press demands for government action and do participate in collective action initiatives as well, at least in São Paulo. So, in practice, the distinctions some militants draw among NGOs assisting the disabled may not be as sharp as they believe. As Young (2011) has observed, analysts should recognize, “the state’s power to promote justice depends to a significant extent on the active support of its citizens in that endeavor” (p.169). Although her argument did not refer to Brazil

specifically, it helps clarify the point that the efforts of many service organizations are indeed important in promoting the wellbeing of Brazil's impaired population. Young has suggested compellingly that neoliberal reforms have privatized many state activities and restructured much social spending in developing nations (including Brazil), resulting in a relative lack of capacity to respond to the needs of the population with impairments. Thus, the argument that it is the "government's job" to assist the disabled and service-oriented NGOs should not do so, may actually result in fewer services for the impaired since the public sector has so little capacity to tackle such responsibilities. This scenario may well be an example of the classic aphorism that advocates, "should be careful what [they] wish for."

Interviewees argued that the disabled themselves constitute a group that can take at least partial responsibility for seeking justice for their population. As one disability NGO leader put it,

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 and life-choosing, with responsibility for the choices made.<sup>80</sup>

NGO leaders also argued in interviews that since the vast majority of disabled people are not very savvy in politics and advocacy, NGOs therefore need to encourage the disabled to learn about the political issues affecting them, and help them do so by offering basic civic education. Indeed, participation is a key concern for many disability rights organizations. To gain an appropriate level of inclusion in society, disabled people need to be actively present in

public decision-making that affects their rights and quality of life. A disability rights advocate and NGO leader articulated this concern in an interview with me,

Until we have effective participation of these people [disabled], it will be difficult to change the rules of the game. It is hard to effectively promote changes to improve the life conditions of persons with disability while they are not present [in public spaces]. If they don't participate in decision-making and in decisions concerning establishing priorities in private enterprises, in government or any other sphere of society, they will be continually excluded.<sup>81</sup>

As Michalko (2002) has argued, without being part of the public dialogue and being regarded broadly as an essential part of the citizenry, disabled people are unlikely to come to enjoy the status of 'full citizens' (p.148).

But securing the participation of the disabled in politics is not their responsibility alone. Society at large has long posed attitudinal, communication, and other kinds of barriers that have prevented the full participation of the disabled in political, social and cultural life. Therefore, addressing the long-standing exclusion of the disabled in society and the prevailing public attitudes that underpin it is too challenging a task for one or two actors alone to address. Stroman (2003) has offered an account of advocacy in which multiple groups are involved to promote the inclusion of the disabled in society. The range of actors he envisioned as engaged goes far beyond currently participating Brazilian NGOs to include informal-natural advocates, self-advocates, legislators, public employees of municipal, state and federal agencies and councils that promote disability rights, such as Municipal and State Councils of Persons with Disabilities, private organizations and associations and publishing and media

firms. His account makes clear that social inclusion for the disabled in Brazil is unlikely to occur unless many groups and actors participate in efforts to secure it. Following Charles Taylor (1992), Brazil's people need to develop a shared horizon of significance, or shared commonalities of values, through a common participatory political life (p.52). This ultimately will broaden dialogue in Brazilian society concerning the possibilities of democratic politics, which Taylor saw as a necessary condition for mutual recognition of difference.

### **Liberal Conceptions of Justice and Democracy: the Implications**

Citizenship advocacy efforts by Brazil's disability NGOs, however conceived, have emphasized individual rights. Building on the liberal values of the Brazilian Constitution of 1988 (discussed in Chapter 4) and the UN Convention on the Rights of Persons with Disabilities (discussed in Chapter 5), such as freedom, equality and autonomy, the nation's disability NGOs have embraced liberal democratic discourses and practices that define full citizenship as strengthening the individual rights of the disabled to access to education, employment, leisure and many other social domains. This section highlights the limitations of this liberal framework for securing full citizenship for the disabled. The analysis of the NGOs' discourses across several genres (reports, websites, interview transcripts) reveals difficulties with their efforts as they relate to including severely impaired individuals particularly, as free, equal and self-governing citizens.

To recap several key points briefly, the Constitution of 1988 had at its foundation a formal conception of citizenship as fixed in individuals as autonomous vessels of universal political and social rights. Daneen (2009) has pointed out that the central role of rights in

modern liberal democracy is based on the priority of the individual relative to the commons or community (p.306). In these conditions, if everyone is guided by their self-interest, it will be difficult to convince society at large, the non-disabled majority, that it is in their self-interest to include the disabled minority as full citizens.

But self-interest is not the only factor that determines citizen participation. As Schneider and Ingram (1993) have reported, citizens access and internalize cognitively messages not only through observation of politics and media coverage, but also through their direct, personal experiences with public policy and presumably with members of the population in question. These experiences tell them whether they are viewed and treated by the government as objects or as subjects, whether they are atomized individuals who should deal directly with state bureaucracy to press their claims or whether they are participants in a cooperative process joining with others to address problems collectively for the common good (pp.340-41). Thus, as these scholars concluded, citizen orientations toward government determine their participation patterns. They may choose not to assign priority to the individual relative to the whole or they may take an alternate course. Liberalism certainly leaves them free to make the decision for themselves and as they may see fit.

The UN Convention sought to strengthen the individual rights of ‘persons with disabilities,’ who in the liberal view, are understood as having powers of reason and free will (Reinders, 2000, p.16). Nonetheless, as Reinders has contended, many intellectually or severely physically impaired individuals do not fit into this definition of ‘persons,’ because they are not independent moral and political agents. Under the Convention, this fact may imply that they formally do not possess standing to receive equal concern and respect compared to others who do enjoy such potential capabilities. Put differently, equal treatment

and respect of these individuals cannot be justified by imagining they can reciprocate such behavior. This fact implies, as Reinders (2000) has suggested, that society's responsibility for dependent others cannot be predicated on a liberal conception of persons as beings who can enter contractual relationships conditioned by analyses of their expected individual and mutual costs and benefits (p.17). Rather, Reinders argues that such responsibility is moral, embedded within a network of social relations, when we give because we have been given, without expecting reciprocity from those who have nothing material to offer (Ibid). Reinders is right that such social relations are solidary in nature rather than economic, and many intellectually or severely physically impaired individuals may offer a great deal without being aware of direct or indirect benefits, without necessarily being conscious of their giving or being able to articulate it.

While all those NGO leaders I interviewed agreed that active citizen participation is indispensable to promote justice, the disability rights movement will continue to need to find modes of engagement that promise benefits to all citizens with impairments. Advocacy is not only the domain of disability rights NGOs or individuals with impairments. Instead, effective activism implies social change and that process, or better, complex set of processes, can only be secured with time and successful social framing of disability rights not as a special interest, but as an appropriate concern of all of Brazilian society. As the story below illustrates, the broader public in contemporary society has found reasons for accepting responsibility for caring for the severely impaired. Reinders (2000) argues, rightly I think, that such reasons rest on collective, and not liberal values, and the narrative below supports his view. The conclusion that follows from this is that responsibility derived from collective values is more favorable to acceptance, care and inclusion of the markedly disabled than are traditional

liberal values. The former will also be conducive to a stronger democracy, by including in politics previously excluded voices and perspectives, as well as those who cannot offer “a perspective.”

I conclude this chapter by recounting a story shared by one interviewee.<sup>82</sup> In late June 2011, in one of the municipalities in the state of São Paulo, several public schools took their students with impairments to visit a farm established in the 1800s, which had taken no steps to ensure accessibility for the disabled. One of the most visited places at the location was a belvedere, from which there was a beautiful view, but no individual with impairment had ever visited it since it was not accessible. The path to the overlook contained large stones and an old bridge. Teachers, school staff and family members overcame the challenge through careful preparation, training and on-site improvisation. They all were determined to allow the children access to the view, and 80 impaired children visited the site in one day. A total of 160 disabled children visited the farm and the summer house because a few experienced professionals with impairments from a disability NGO instructed teachers, family and firefighters on how they might make it possible. The important turn that made the previously impossible feat feasible was the determination of everyone involved to make the place accessible for children with severe impairments so they could enjoy the same opportunities as any other child. Those involved arranged access on the spot to ensure inclusion, evidence of a positive value valence that will need to be broadly cultivated if this group is to enjoy full citizenship rights in Brazil in the long run.

## Summary

This chapter has explored the major conceptions of justice for the disabled in Brazil as these could be gleaned from disability NGO reports and websites and interviews with their leaders. I sought to describe what these views suggested for efforts to secure full citizenship for the impaired in Brazil. After providing a brief overview of disability NGOs in Brazil as background, I examined the claims these organizations offer concerning the meaning of citizenship for the disabled and how it might most effectively be ensured. An investigation of relevant NGO discourses revealed broad adoption of liberal conceptions of justice. In the chapter's final section I analyzed the implications of that stance for social inclusion of Brazil's severely and profoundly disabled citizens and for development of the nation's democracy. Drawing on Reinders (2000), I argued that the notion of liberal citizenship articulated by disability rights NGOs in particular cannot provide for inclusion for individuals with severe impairments. Any rationale for social acceptance and inclusion of this population must ultimately rest on collective values rather than liberal ones. I offered a hopeful account of one episode provided by one interviewee that suggests that such is surely possible in Brazil in the long run, but public policy and interested NGOs alike will need continuously to make the case in the public square for such an orientation and for how and why it matters to the nation.

## **Chapter 7**

### **Conceptions of Justice, Responsibility and Blame**

This chapter explores the conceptions of impairment, disability and justice articulated by interviewees with disabilities. I discuss their perspectives as these views and experiences provide an important context for how justice is understood, lived and imagined by people with impairments. Chapter 5 offered an analysis of legal and policy-related comprehensions of disability. Here, I complement that framing by examining the understandings and experiences of individuals with impairments. These perspectives are not formed in isolation by individuals alone, but are also influenced by contextual factors, including prevailing social values and attitudes of family and loved ones. These may be either enabling or disabling. Understandings of impairment and disability inform impaired interviewees' understandings of justice. Not only do these ideas concerning what constitutes just action reveal diverse notions of what is fair for the population with impairments, but they also relate to a rhetoric of blame directed at society at large, some people with impairments and certain medical and educational experts.

### **Conceptions of Impairment and Disability**

Few would argue with the proposition that how most aptly to consider impairment and disability is hotly disputed. How one thinks about these concepts is of central importance to how one conceives of justice for disabled people. This section explores the views of impairment and disability articulated in interviews I conducted for this study with impaired respondents who reside in São Paulo.

Scholars and medical professionals have often conceived impairment and disability in terms of the biological features of a person that deviate from society's culturally established normality—physical, intellectual and emotional attributes. Discussing disability from a medical perspective, treating impairment as illness, some scholars have used health-related language of symptoms, syndromes and diagnostic typologies to describe and analyze impairment and disability phenomena.<sup>83</sup> However, Shakespeare (2006) has argued impairment should be viewed not as intrinsic to a particular individual, such as nature and severity of a specific condition, but as, “related to values and attitudes of a wider society” (p.35). As one of my visually impaired interviewees put it, consistent with Shakespeare's view,

The problem is the establishment of a competitive society, which values perfection, aesthetics, people who theoretically have no difficulty. The more perfect you are, the better accepted and valued will you be. [...] When a person demonstrates a "defect," for example, physical or sensory impairment, that person is placed on a lower level. We're trying to lift these people to the same level of people without disabilities. We were put so low that to reach the same level, it will take a long time.<sup>84</sup>

Critical scholars Pothier and Devlin (2006) have also contended that depending on what is valued, or perhaps overvalued, in a society, specific personal characteristics may be understood as defects (p.5). As Omote (2004) has explained, no biological feature or attribute is deviant just because it differs from the norm; in fact, any quality can be interpreted and treated as a case of deviation, depending on who possesses the particular feature and the context in which the judgment occurs (p.292). Thus, the notion of impairments remains controversial and has broad implications for allied definitions of disability.

I am persuaded that Shakespeare (2006) is correct and that although there is no disability without impairment, it 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 discussed in Chapter 2 argue. Some impairments may be so severe that they limit function; irrespective of how society is organized (Hartley, 2011, p.121). Thus, disability is the result of an interaction between an individual and structural factors or, put differently, it is the consequence of the relationship between influences intrinsic to the individual (nature and severity of the impairment, their own attitudes to it, their abilities and personality) and contextual elements (enabling or disabling environment, wider cultural, political, social and economic values, attitudes and interests) (Shakespeare, 2006, pp.55-56). As one of my interviewees said, referring to the majority of disabled Brazilians living in poverty and lacking access to basic healthcare and technology:

In the Brazilian context blindness is equivalent to death, or worse than death. I am of the opinion that blindness by itself doesn't mean anything; it all depends on the context. Real life depends on the education you have, on the technology you have, but most importantly, the attitude.<sup>85</sup>

I discuss both conceptions of impairment and disability here because interviewees used these terms to convey their experiences of inferiority and emotional injury within their families and/or wider society. 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 illustrate the complexity of the attendant issues and the similar intricacy of the solutions that must be developed to address them.

Many of the discourses of impairment and disability internalized and articulated by disabled individuals imply a biomedical model, as discussed in Chapter 2. Overall, by locating the impairment problem with the person, advocates of this perspective view such individuals either as victims of their impairment or having physical problems that must be cured. Although many physicians realize that some conditions cannot be “fixed,” by adopting this approach society agrees to “treat” the person rather than address potentially relevant contextual factors. When interviewees identify themselves as having a “problem,” or as being “unproductive,” their rhetoric suggests they have internalized the biomedical model. When disabled people adopt this stance, they ironically and implicitly justify society’s discriminatory attitude toward them.

Ann Davis (2005) has observed that American society invested in physical accessibility, “to enable some disabled persons to have greater access to public buildings and have made changes that enable some persons with disabilities to be physically present and reasonably safe in the workplace and the classroom,” but they are still not effectively “happy, productive, and successful” (pp.197-98). As she has argued, “there are many more subtle and pervasive mechanisms of inaccessibility and exclusion that may both exacerbate disability and limit the participation of disabled persons in the life of the society” (p.198). Davis’s observation suggests that when disability is reduced to a set of quickly identifiable factors, the

conceptions of justice that result will be simplified reflections of reality and will not account for the complex lived experiences of disabled people.

Charlton (1998) has perceptively noted that attitudes toward disability and impairment are, “individually experienced but socially constituted” (p.51). That fact implies that the attitudes of the people with impairments I interviewed are influenced by how they and their families see their disability as well as how others in society view human diversity and social disadvantage. Charlton has further explained that society’s negative beliefs and attitudes toward impairment and disability are eventually also internalized by individuals with impairments (p.70), which makes finding a starting-place from which to launch efforts to change those beliefs and attitudes more difficult.

To address that hurdle, Anita Silvers (2003) has suggested a neutral notion of disability, which follows neither the social nor medical models. Silvers attempted to foster a productive dialogue between bioethicists and disabled people, raising questions regarding the intrinsic “badness” of disability and of reducing its incidence as unquestionably good, while also according a priority in the distribution of resources and services to all impaired individuals regardless of their individual needs, limitations and difficulties. In my view, Silvers conflates disability and impairment in her account: bioethicists address biological traits—i.e., impairments, mental illness, syndromes—while disability activists deal with disability. I disagree with Silvers’ criticism of providing priority service to all people with impairments in a neighborhood post office line. As Silvers (2003) has noted, “Sitting in my wheelchair in the line, I am more comfortable than anyone standing” (p.478). What if Silvers only had 64 adult diapers allocated to her by the government, as my interviewee mentioned in

Chapter 2, and waiting in the line meant using a diaper longer than appropriate? What if the weather was rainy, and she was an individual in a wheelchair and dependent on public transportation who would not be able to move a non-motorized wheelchair and hold an umbrella over herself simultaneously? These are real life examples and her story of feeling quite comfortable while waiting in a post office line needs to be put into the greater context of the lives that other people with impairments experience on a daily basis.

Davis (2005) has argued that although perceptions may be more difficult to change than policies, the first listed are not “immutable” (p.191). Generally, individuals with impairments are viewed as badly off or unfortunate in Brazil, maybe because of pain or as a result of the numerous difficulties they face every day or perhaps because they connote a negative image of the future or possibly for other reasons. I was struck therefore to learn that several of my interviewees conceived of their impairments not only as conditions of inferiority and limitation, but also as providing identifiable and personally significant gains in life attitudes and worldviews. Many of my respondents commented on the importance of their family’s influence on the formation of their own attitudes toward impairment, an argument to which I return below. Two sets of discourses emerged across 11 interviews on conceiving impairment and disability: as a loss (and sometimes alternately as a gain) and as intrinsic inferiority. Related to these discourses, interviewees offered several comments on the importance of family values in the formation of attitudes toward their impairment(s) and disability.

The notion of inferiority emerged in several interviews, unrelated to specific impairments. It was especially clear when a young man with an intellectual impairment

observed, “I am special; I have a problem.”<sup>86</sup> He believed he was entitled to receive a disability benefit from the state to cope with his “trouble,” to buy medicine and to survive, but the government denied his request. A social security doctor informed him that he could walk, run and jump, so he was able to work and was not entitled to the support. I have no way of knowing whether this young man thought of his intellectual impairment as “his problem” before or after the incident with the state physician he recounted in his interview, but this story illustrates how he internalized the professional (in this case, medical) discourse of attributing the perceived “problem” to the individual, who thereupon needs to find a solution to his or her “condition.” And when they cannot, they feel inferior for many reasons—for not finding employment, for not having income, for having multiple health issues, for facing discrimination in their family and neighborhood—just to mention a few. Another discourse of inferiority could be identified in the narrative of a young deaf individual in his interview:

I see a deaf person in a hearing society as some sort of delay, and of course it depends on people themselves, but I see that deaf people lose a lot of information compared to those who are able to hear, they are far behind in this regard. The information that is communicated is quite impoverished, and the society begins to see the deaf as incompetent and ignorant. So education must be a way that the deaf can catch up. But right now, I see it unfair to be marked as incompetent.<sup>87</sup>

Another interviewee brought up the privileged standing enjoyed by nondisabled individuals in his view:

People without disabilities consider themselves different, or privileged. There is a feeling I have sometimes that people with disabilities are not considered effective. We

are called damaged and several other harming expressions. I have a feeling that it was socially constructed. I think there is still no sense of equality. Of course it has exceptions, but if you ask people who live in São Paulo, certainly a huge majority does not consider people with disabilities like them, in the sense of rights and capabilities.<sup>88</sup>

In general, interviewees saw disability and impairment as closely related to inferiority. The experiences of individuals with impairments are different: some had internalized this diminished sense of self and expressed it in their interviews while others had sought to overcome it and did not evidence it when they spoke to me. As one physically impaired woman observed, “I thought I would never go out, flirt, have a relationship, or get married.”<sup>89</sup> Nonetheless, she was engaged to marry and planned to have children, go to college and work. Similarly, interviewees shared mixed discourses of impairment and disability as a loss (of opportunity), or at times as a gain (of motivation, willpower, positive worldview) in their lives.

On the whole, the interviewees’ views of impairment and disability as loss shared a perception of the individual as an unproductive burden to society, in the spirit of the biomedical model. This perspective has undermined the basic skills and capabilities of individuals who have adopted it for many years. More, even when nondisabled working professionals favor the inclusion of disabled employees in the workplace, their stance concerning doing so is inconsistent, as several interviewees commented. One of my respondents shared his experience of observing managers justifying why they could not hire impaired individuals for their areas:

I heard managers saying, ‘I am in favor of inclusion, we need to give opportunity to these people, they can be useful, but here in my area it’s complicated. We need to be highly productive here in my area, but I am very much in favor of inclusion.’ You see, the person has a discourse, but it is contradictory. This equality does not exist culturally yet, just politically and legally.<sup>90</sup>

Overall, there are fewer opportunities for people with impairments compared to non-impaired individuals, as one deaf interviewee noted: “For the Deaf, there are fewer opportunities to take advantage of. Because of [better] communication, those who hear have a choice to learn or not, but we face a barrier if the information is not communicated. If this barrier is removed, the deaf will have a choice to learn or not, it will depend on us. But now we have this barrier.”<sup>91</sup>

People with physical impairments experience difficulties in other spheres, including for example, finding accessible housing. A young woman shared her experience of looking for housing she could access in her wheelchair in an interview with me: “We want to rent a house, but we can’t find a single story one, without stairs, for easy circulation.”<sup>92</sup>

However, my interviewees also perceived impairment and disability as yielding insights and motivations for the individuals living with them. One respondent with multiple impairments (blind, hearing and physically impaired) reported that since acquiring his impairments he discovered he had new talents and a motivation to learn new things that he previously had never imagined he was capable of learning:

First, I learned to play the small guitar, and then I thought if I could do that, then I could learn Braille. When I learned Braille, I thought, oh well, if I could do that, then I

could start walking with a walking stick. Now I can go anywhere across town [São Paulo is a big city, with more than 10 million inhabitants], wherever I need to. So you do not really need your vision. ... You need your goals to get wherever you want. Sometimes I have sad thoughts, but you have to have a lot of willpower.<sup>93</sup>

Another blind woman said she had developed a different perspective concerning life as she coped with her impairment: “I began to appreciate things I did not before, and vice versa. Today I don’t see life through eyes, but through my heart, differently. I am blind for only three years, but I am not frustrated because of my impairment.”<sup>94</sup>

Many interviewees perceived family support as a very important factor in their own attitudes to impairment and disability. This assistance is not so much material although, of course, ample monetary resources can assure better access to healthcare and technology, but more psychological and moral encouragement, as the examples and quotations that follow show. Shapiro (1993) has recounted the story of Ed Roberts, the founder of the disability rights movement in the United States, whose parents fought for him since he had polio complications. Roberts later suggested that that experience of accompanying his parents in their advocacy efforts allowed him to develop, “the most important skill you can learn to be successful” (p.44), referring, as I understand, to the profound sense of resilience and rebelliousness that Roberts demonstrated throughout his undergraduate and graduate education at the University of California, Berkeley.

Some of those with impairments who I interviewed enjoyed the strong support of their families and these encouraged them to seek personal and professional fulfillment in life. As one blind interviewee noted, he had been raised to understand and value his own potential:

The most important variable in my attitude to disability is my parents. They considered and treated me as somebody with a lot of potential, and never as somebody as a victim. I think that really shaped my life and my attitude towards blindness. And I think of that as an incredible help, because I've seen many people with more opportunities than I had, with access to good education, access to assistive technology, but they accomplished a fraction of what I did. Not because they were not intelligent, but I think because they didn't have the same attitude, the same understanding of themselves.<sup>95</sup>

This deaf man attributed his family's support for nurturing his positive attitude toward his impairment:

My experience, for example, as a deaf individual, and a little different from other disabled people because my family is deaf, my grandparents were deaf; my parents also have a deaf sister. And I grew up in a family where we had a very good communication, because we talked a lot. We used sign language, and whenever I saw my neighbor I thought he was very odd, because he did not use sign language. He always moved his mouth, his lips moved, and I pitied him, because he did not know how we communicated. I told my father that they did not know signs, and my father responded that maybe I could help him learn. And with time I grew up and realized that most people in our society are different from me, and I'm deaf as a minority, with a different culture. I saw other people as disabled, and thought I was normal in that sense.<sup>96</sup>

The strong presence of the biomedical model in Brazilian society is illustrated in the experience of one deaf interviewee, who pointed out how medical professionals are sought out often by families for recommendations for child education and upbringing:

Sometimes, when the family has an impaired child, it will look for a doctor, but will not accept a deaf teacher to give her advice. The doctor will give the techniques that he thinks right. It is up to society to give information. Today I understand this, but I continue being angry with doctors, because most of them do not have information on how to live together with a person with disability. They know very basic things, for example, in a deaf person they examine the ear, trying to cure the problem of the ear. The doctor knows that cure is not possible, but he can't tell that to the family, he does not want to traumatize them. This situation is worse, because it affects the child negatively. It can be a shock to a family and painful to know that their child is deaf, but it's probably better, since the family will get information sooner. There are also some specialists who force deaf children into learning oral language, which in many cases delays the development of the child. Health professionals and the society need to change their view concerning disability.<sup>97</sup>

Another deaf individual, who experienced difficulties growing up as the only person with auditory impairment in a hearing family, believed that this lack of acceptance and support affected his attitudes in life. His family tried to limit his use of sign language and forced him to use oral language. Based on his experience, he now insists something must be done to ensure that impaired people experience acceptance from childhood onwards. In his view, social attitudes must shift if discrimination and fear are to be overcome.<sup>98</sup>

These interviewee accounts did not constitute an isolated view of disability, as a “unidirectional assault on identity,” as Charlton (1998) put it (p.57). Because the people I interviewed do get out, communicate with peers with and without impairments, work and study, they have opportunities to push back and fight prejudice. Their conceptions of disability and impairment would likely have been quite different had they lived in rural Brazil and never seen another individual with impairments or ventured out of their own neighborhood or village or never worked or studied. As Shakespeare (2006) has argued, disability depends very much on contextual factors and on an individual’s own attitudes toward impairment and my respondents made clear that these in turn depend strongly on family support.

### **Conceptions of Justice, Responsibility for it and Associated Rhetoric**

This section explores the conceptions of justice as imagined and lived by the individuals with impairments whom I interviewed. The experiences and ideas of my respondents about what was just for them were diverse and the capabilities approach represents a helpful framework through which to understand them. While the social model of disability does not explicitly address personal characteristics, the capability approach includes human diversity by including and accounting for individuals’ personal traits and resources, which in certain social, political, economic, and cultural environment may lead to disability, or capability/functioning deprivation (Mitra, 2006, pp.241-42). Together with conceptions of justice, interviewees with impairments also articulated notions about who is responsible for justice. Respondents’ notions of responsibility for justice can be grouped into personal and shared responsibility accounts. Individuals with impairments who believe they need to take

initiative and show to the wider society they are capable and productive and ready to be included articulated a personal responsibility perspective. Interviewees offering collective responsibility accounts conceived of obligations in shared terms, articulating requirements of the disabled and non-disabled alike, including ongoing dialogue.

**Justice and Equality.** The capability approach differentiates between competence (practical opportunities) and functioning (actual achievements) levels. This view suggests that the same opportunities will not necessarily bring equal advantages to disabled and nondisabled individuals (Sen, 2005, p.154). Several interviewees embraced the idea of justice as equal opportunities, but with some differences in the meanings they attached to the construct. As one interviewee explained:

Obviously, you have to have equal opportunity for all, it has to include education, and you cannot educate a child with disability if he has no accessible public transportation, so it's an ecosystem, you cannot try to solve a problem without focusing on a large collection of elements. You also need common sense, but you cannot put it in legislation. For example, you cannot have a blind guy complaining that he wants to be a cameraman and people won't let him. At some point you have to draw the line, a dynamic line. What is unfair today may not be unfair 10 years from now.<sup>99</sup>

When there are challenges related to work, for example, the person without disability may end up getting more opportunities, and I will not get them and end up labeled as incapable.<sup>100</sup>

We need to work hard [to attain justice], because even if opportunities are equal, the training is never equal, and we are never received as an equal. This is what we have to change in the society - the vision.<sup>101</sup>

As the last quotation just above shows, some respondents did not believe that equal opportunities would result in equal advantages among individuals with different impairments or even among persons with similar impairments. The capability approach helps to illuminate how ‘impairment’ is converted into ‘disability’ in practice, since disability as these respondents see it is a deprivation in terms of capabilities or functionings, opportunities or actual achievements (Mitra, 2006, p.237). This denial results from the interaction between an individual’s personal characteristics and available resources and their social, economic, political and cultural environment. As I noted in the previous section, attitudes towards impairment and disability, family support and available material resources, all contribute to producing an enabling or disabling environment for individuals and thereby, at least in part, to their eventual achievements.

In raising the question of equality, the capability approach requires respect for the range of human diversity and the potential inherent in each individual to develop by accessing the resources and rights afforded them. This perspective highlights individual differences and realities. For example, as one of my deaf interviewees reflected,

[J]ustice is when all people have the needed information and can coexist. This kind of knowledge and experience causes them to have equality in the relationship with people with disability. They'll start to respect their limitations and it will be reciprocal:

people who have disabilities will respect the limitations of people without disability, and people without disability will respect the limitations of people with disability. I as a deaf man have my limitation, but I have my culture, my language, and if I do not have a convivial experience with other people, I will have no information about them. [...] Someone who grew up and studied with the deaf will know of their limitation, about this human diversity, and will respect these limits.<sup>102</sup>

This deaf young man emphasized the importance of social relations in attaining justice suggesting, as Wolff (2009) has done, that we should focus on integrating equality as, “a matter both of distribution and of social relations” (p.116). Meanwhile, some interviewees imagined justice in terms of equal rights:

I imagine people having access to public transportation, education, including high education, we should be able to require companies to design subway and bus stations that are accessible, we won't have money to buy a car for every person with disability. That should be part of our process. I don't think the rights of any individual are static; they are a process, because just as today I am denied the right to drive a car, 10 years from now I may drive a car. But if 10 years from now anybody can drive a car by pressing a button and inputting an address and the society doesn't let me be a taxi driver, then that's unjust. So the rights are constant, but because the society, culture and technology evolve, they can be redefined.<sup>103</sup>

For me, it's fair when everyone has full access to education, culture, leisure, work and other institutions. The day that happens, I'm the first to eliminate the Quota Law, I am the first to eliminate the [tax] exemptions for the purchase of vehicles, free pass in

public transportation, and all these affirmative action initiatives. They only exist because the world has not been just to people with disabilities. I do not think these actions have to stay forever; they should end at some point. <sup>104</sup>

These quotations overlap with Wolff's (2009) comment that the enjoyment of rights or functioning is conditional on performing a series of actions within an agent's power (p.117). These acts may incur costs and risks and Wolff was keen to point out that the capability approach needs to consider which actions, costs and risks are required of individuals for them to attain a particular level of functioning (p.118). In emphasizing equal opportunities, the implicit assumption underpinning the concept as aspiration is that individuals with impairments should be accorded access to the competitive, individualist market, even though many of these people will not be able to function with parity within it without ongoing support (Rioux & Valentine, 2006, p.54). The decision to work outside the home for many people with impairments may incur the risk of facing day-to-day discrimination at work, which would not have happened had they simply stayed home (Wolff, 2009, p.121). To address equality appropriately, Wolff (2009) envisioned creating a society of equals through status enhancement, which entails modifying technology, laws, the built environment and public understanding (p.128). Although modifying social position takes a long time and typically entails high material costs to be effectual, its benefits lie in its non-stigmatizing and inclusive nature, which favors society as a whole (pp.131-132). Wolff's view of a society of equals is similar to the perspectives articulated by my interviewees as they sought to integrate the idea of enjoying a certain level of functioning with the reality of social relations deeply sensitive to differences (p.122).

Silvers (2009) has argued that differences need to be appropriately conceptualized and distinguished, because distinct categories of dissimilarity produce different strategies for achieving justice (p.169). First, denying or neutralizing difference results in valuing homogenization and privileging common levels of ability as the normal, which may extend injustice rather than reduce it (Silvers, 2009, p.172). Second, mitigating distinctiveness seen as deficiency, attributable to existing biological loss or inadequate social interaction, will only bring disadvantaged individuals up to the point of perceived elimination of the deficit, and do nothing beyond that threshold, even if the person has the potential to do more (p.184). I agree with Silvers (2003) that, “not every limitation is a loss—and certainly not an intolerable loss” (p.482) and that “justice is not exhausted by remediation” and its concern should be broader than focusing preeminently on the worst off (Silvers, 2009, p.184). Finally, Silvers lays out a third strategy of embracing dissimilarity, seen as talent, arguing that justice needs to be concerned with developing the capacities of marginalized people as much as it should value mitigating their deficiencies (p.184). This last argument is consonant with CRPD’s objective of not only securing the inclusion of disabled people in society, but also ensuring their development to their ‘fullest potential’ (UN, 2006, Art.24b).

**Justice and Responsibility.** Different concepts of equality imply different conceptions of responsibility. Often, internalized norms of inferiority cause many disabled to believe that even from their disadvantaged positions in society, they bear more responsibility for their inclusion in wider society, for social acceptance, than do their nondisabled peers. As two of my respondents observed:

I think the responsibility [for justice] is greater for people with disabilities, because in my perception, people who don't have disabilities and have no contact with those who have disabilities, have no idea how it is. You cannot demand something of the person, if she did not know what's being required. People who have no contact with someone who has disability, they have an excuse of not knowing that the problem exists, but it won't be an eternal excuse. But the ultimate responsibility is mine, I have a disability [...] It's up to us to start this movement, because the society is not worried about it, does not know that this problem exists, and we know this is still far away. I think it is more people who have disabilities to change that.<sup>105</sup>

The society is not the only one to blame [for injustice]. There are many people [with disability] who received LOAS [*Lei Orgânica de Assistência Social*, a law that instituted disability benefit], and get comfortable with it. I want more than that, I do not have to content myself with a minimum salary for the rest of my life. But there are many people who are not like that, I want to produce, I am capable, I want to show my ability. I think that we need to show to the society that we are capable, that we are here, ready to be included into the workforce and to participate.[...] We are here to participate, to add, not to be a burden or to subtract.<sup>106</sup>

Nonetheless, what these interviewees do not reach is the importance of the social and economic base from which such individual efforts begin. As Young (2011) has contended, it is reasonable to expect more, on average, of those persons who are in relatively privileged positions in these terms compared to those without such advantages (p.181). However, both the advantaged and disadvantaged who participate in the production and reproduction of unjust

structural processes have a shared responsibility in organizing collective action to make those structures more just (Ibid, p.184).

The blame language in the discussion of social problems can be inappropriate and unproductive, as Young (2011) has observed, for several reasons. These include dividing people when cooperation is needed and encouraging defensive reactions and blame-casting behaviors (pp.116-117). Also, blame-laden language reflects a specific understanding of the root causes of any given disability and consequently implies only certain acceptable ways to address it. For example, when asking interviewees about disability benefits, I was able to identify a “blame discourse” that would isolate “accommodated” individuals with impairments who would supposedly be satisfied with receiving benefits (roughly 300 USD per month), instead of demonstrating readiness and willingness to work and participate in society.<sup>107</sup> Echoing this argument, three of my interviewees justified the application of tougher procedures for disability benefits screening, suggesting that otherwise, people would take unfair “advantage” of the support provided. While one interviewee with multiple impairments who receives state support thought the process of approval needs to be tough and complex, so that undeserving individuals with impairments will not take advantage of it,<sup>108</sup> another respondent with an intellectual impairment thought the review process was unfair and subjective. He has twice been deemed ineligible for public aid.<sup>109</sup>

It is not difficult to understand why thousands of disabled people are “accommodated and satisfied” with their disability benefits when the unemployment rate among adults with impairments is so high, discrimination in the workplace is frequent and their entrepreneurship is poorly supported. Joining forces and assisting each other seems to be an appropriate attitude

to address this difficult constellation of conditions for as Shakespeare (2006) has suggested, helping disabled individuals enhance their self-esteem and self-confidence transforms their lives as much as access to appropriate facilities and medical care do (p.61). Representatives of the Deaf community also direct “blame rhetoric” toward educators and healthcare professionals insisting that these experts and society in general have an erroneous concept of deafness and Deaf people that harms such individuals and hinders their development.<sup>110</sup> These advocates challenge the norms that underpin supposed professionals’ right to decide their needs and the kind of help they should receive. Shakespeare (2006) has similarly argued that purported technical knowledge should not be permitted to run roughshod over impaired individuals’ choices and needs (pp.191-92). Jean Harvey (1999) has argued that such blame rhetoric should not be dismissed. She saw an important role for public expressions of regret in aiding the process of growth in moral awareness in society and in mending the relationships that have been seriously distorted between the victims of opprobrium and those enacting it (pp.136-137). Moreover, offering a heartfelt apology can be a moving expression of an institution’s (or individual’s) moral integrity, as Harvey (1999) has suggested (p.139).

These discourses constitute attempts by disabled individuals to regain control over their lives and to be independent. However, remediation of individual scale injustices, while critical, is not sufficient, as it cannot account for the socially constructed responsibilities of the broader society (Wolgast, 1987, p.25). There are limitations to (liberal) individualism, as one of my interviewees commented:

Things are changing [in terms of social inclusion], we're improving, but I do not see the effective humanization of relations between people in the short and medium-term. This

humanization exists, but it has a limit, which is the limit of your individualism. The culture of individualism hinders inclusion.<sup>111</sup>

Besides grasping the importance of liberal individualism and its impacts on them and the ways in which their own efforts have contributed to its ascendancy as a view, it is important for people with impairments to understand the degree to which they contribute to the reproduction of the continuing dominance of the biomedical model in their everyday lives.

In addition to a personal responsibility discourse, interviewees also articulated, to a lesser extent, a discourse of shared responsibility. When expressed in these terms, disability is seen as a collective, rather than an individual issue:

I think everybody should have some minimal awareness of disabilities, but of all, the awareness should be of the need to dialogue, for the conversation, even if it's just a couple of questions. Simple dialogue can go a long way.<sup>112</sup>

The path [to make Brazilian society more just] is to make our society more solidary, by which I understand people educating their children to compete less, to share more, to be more human, to respect other people, and more than respect, value other people. If we can put this social gene, this cultural gene, this emotional gene in our children, then I think the situation changes. Of course it will take generations, but it can be done.<sup>113</sup>

Both solidarity and mutuality are vital for the advancement of Brazil's disabled people. Young (2011) has suggested that people in solidarity assume a shared responsibility when pursuing the goal of improving social institutions and practices to make them more just (pp.121-122). Young drew on Derrida's notion of political friendship in developing her claim

for solidarity to articulate a concept of shared responsibility, “Solidarity is a relationship among separate and dissimilar actors who decide to stand together, for one another” (Young, 2011, p.120). Notably, interviewees were not talking about dialoguing or joining with others with similar impairments. Their sense of solidarity and need to dialogue was not rooted in their particular impairment. Instead, they professed a desire to join a conversation with other ‘dissimilar actors’ to change their collective situation and to share responsibility for action. Unlike other discourses of personal responsibility, which evidenced or implied inferiority due to impairment-related limitations, these respondents seemed to relate to the wider society on more equal terms when they called for dialogue. This approach is consonant with Martha Minow’s recommendation to approach differences through dialogical processes, which brings excluders and excluded together, reducing the psychological as well as physical distance between them (Minow in Silvers, 2009, p.168).<sup>114</sup>

## **Summary**

This chapter has explored the major conceptions of impairment, disability and justice in Brazil as these could be gleaned from interviews with people with impairments I conducted in São Paulo. I sought to describe what these views suggested for efforts to secure full inclusion and participation for disabled people in Brazil. After providing a brief overview of the meanings assigned to impairment and disability by those with such conditions who experience their effects on a daily basis, I explored the conceptions of justice my interviewees articulated in terms of equal opportunities, access and respect. Their notions did not focus solely on distributive ideas of justice, but also emphasized the character and contours of social

relationships as key to social equity. Next, I examined the claims these individuals offered concerning the meaning of justice and who should assume responsibility for its attainment. Examination of relevant discourses, as voiced by interviewees, revealed that those with impairments embraced notions of both personal and collective responsibility for justice in Brazilian society. Respondents also often adopted a discourse of blame that frequently proved isolating and unproductive.

## Chapter 8

### Conclusions and Implications for Further Research

As a dissertation in the Social, Political, Ethical and Cultural Thought (ASPECT) program, one of the central aims of my study has been to develop an interdisciplinary approach to disability and justice that would transcend particular disciplinary insights. If scholarly inquiry can be conceptualized as a matrix in which social concerns represent the horizontal dimension and disciplines the vertical one (Lebow, 1988, p.509), then most societal challenges cut across the domains of two or more disciplines and scholarly insights from those different fields and their respective methods and findings are crucial for addressing major concerns. Also, as Klein (1990) has observed, there is no readily available formula for undertaking interdisciplinary research (p.73). Disability studies as an area of inquiry spans multiple disciplines, including several in the social sciences. Scholars in several fields have also been instrumental in developing theories of justice.

In examining the contemporary public and private discourses concerning disability and justice offered by different actors in Brazil, I drew on ideas offered by various authors representing multiple disciplines, including Iris Marion Young, Paulo Freire, Martha Nussbaum, and Amartya Sen. These scholars have developed democratic and justice theories and some have also contributed to feminist social and political theory. As I conceived this effort, I saw two possibilities to develop an interdisciplinary stance to my selected topic. I could follow Repko (2008) and trace the disciplinary bias in the questions and answers/theories provided by each approach to my subject of interest (p.219), identifying streams of inquiry where discipline-based insights conflict. I could then search for a common

ground among those arguments as a basis for their integration to produce an interdisciplinary conceptualization (p.247). However, I believe that understanding others not only concerns finding common interests and beliefs, but also demands moving beyond personal comfort zones and learning something new about differences with them and ways of bridging those dissimilarities. Moreover, the scholarly thought I drew on in this study already contains multiple disciplinary perspectives and teasing those apart to identify their biases might be difficult in many cases.

For these reasons and as a second option, I imagined I could compare and contrast the perspectives of different stakeholders as articulated in their respective discourses. Young's (1997) concept of asymmetrical reciprocity was helpful as I considered this alternative, as it does not obscure difference among engaged stakeholders and their perspectives and it also takes into account the issue of structural injustice. Furthermore, my ultimate purpose was not to diminish the dissimilarities among interested groups by focusing on their common views, but rather to create a dialogue among different perspectives, in the name of outlining a new understanding of justice for people with impairments while also identifying the social changes needed to attain it.

This chapter is an effort to integrate the different justice perspectives of the stakeholders examined in this research by means of my second (selected) alternative for conceptualization. I leave the ambitious project of attaining justice for the disabled and the social change necessary to secure it, to the future. This stance acknowledges the need for moral humility, when seeking to understand the perspectives of others (Young, 1997, pp. 354-355). As social life consists of plural experiences and perspectives, the democratic

conception of moral and political judgment is best understood as a product of dialogue, in which all affected stakeholders have a voice under conditions of equality and mutual respect, and those engaged are able to enlarge their thinking by learning something new (Young, 1997). After discussing insights gleaned from exploring the views of different stakeholders on disability and justice, I also share my recommendations for further research.

### **The Insights of Societal Stakeholders on Justice for Brazil's People with Impairments**

Before suggesting an understanding of justice that acknowledges the perspectives of Brazilian policymakers, leaders of disability NGOs and citizens with impairments, I first briefly recap here the main points from Chapters 5, 6 and 7. I believe it is important not only to confront different perspectives on what is just for people with impairments, but also to consider how this group is conceptualized by each of the stakeholders, because such frames are culturally and socially foundational.

Brazilian policymakers view citizens with impairments as individuals with limitations, and they therefore have designed policies to target only those who fit the legal definition of disability. The nation's policies, programs and measures have focused on ensuring individual rights, leaving structural inequalities unaddressed, as Young (1990) has warned is a predilection of liberal sensibilities and societies everywhere (see Chapter 4). Brazil's disability NGO leaders view the population they serve somewhat differently. These groups celebrate the importance of individual participation. The advocacy leaders I interviewed saw people with impairments as a group that can take at least partial responsibility for seeking justice for their number. These representatives claimed that to gain an appropriate level of inclusion in society, people with impairments must be actively present in public decision-

making that affects their rights and wellbeing. However, historically, in Brazil the disability rights movement has been organized around forms of disability (physical, intellectual and sensorial impairments), an organizing disposition that persists to the present day.<sup>115</sup> This institutional siloing and fragmentation has limited the collective power of disabled Brazilians in their political struggle (Lanna, 2010, p.54). In addition, the disability rights movement has actively discouraged participation by individuals without impairments, preventing them from voting or otherwise engaging in campaign decision-making (Lanna, 2010, pp.39-40). The NGO leaders I interviewed believed that the UNCRPD represents a helpful tool in overcoming these historical divisions within the movement.

The people with impairments with whom I spoke for this study offered both individual and collective perspectives when describing their roles in the struggle for justice. Brazil's recent census conducted in 2010 revealed that 45 million of the nation's residents live with some kind of impairment, visible or invisible, severe or not, and not all of them are powerless or equally oppressed. Borrowing from Young's (1994) feminist theorizing, I have argued that it is important to conceptualize people with impairments as a collective to maintain an alternative to liberal individualism (p.718). Pressing for individual rights does not help in efforts to frame and address oppression as a structural institutional process (Ibid). As I mentioned in Chapter 2, Young has helpfully distinguished between the concepts of seriality and of the group. To serialize an individual with impairment(s) does not necessarily mean identifying common attributes he or she shares with others, but rather providing a context in which ongoing historical and material social structures are unreflectively reproduced (Young, 1994, p.728). Being a member of the impairment series or similarly, of the women series, does not constitute one's identity: It may give a general idea of the constraints and

expectations that a person might have to address, but reveals nothing in particular about who he or she is, what he or she does and/or how impairment or gender marks his or her life (Young, 1994, p.733). In contrast, a group is a self-conscious social collective whose members share common experiences, perspectives and a joint project that defines the group's collective action (Young, 1994, p.735). This conceptual distinction helps the analyst understand that common action cannot be expected from all people with impairments just because they have disabilities, and that to advance to the level of self-conscious organization in groups, individuals need to be reflective and mutually to acknowledge one another as having shared purposes and experiences. The social constructions that each group of stakeholders have developed of people with impairments has informed their conceptions of justice, which I summarize below.

As discussed in Chapter 5, policymakers conceive of justice as the formal implementation of individual rights. Brazil's Constitution, the UNCRPD and recent human rights policies are built on the premises of liberal individualism. That fact makes it difficult to conceptualize oppression as a structured and institutional process, as Young (1994) has pointed out (p.718). The liberal Constitution of 1988 had at its foundation a formal conception of citizenship as fixed in individuals as autonomous holders of universal political and social rights. The UN Convention sought to strengthen the individual rights of 'persons with disabilities,' who were understood by its authors as possessing powers of reason and free will. Under the Convention, individuals with severe intellectual and physical impairments are not formally recognized as independent moral and political agents and equal treatment and respect of these individuals cannot be justified by imagining they can reciprocate such behavior. Society's responsibility for dependent others must go beyond the liberal conception

for supporting such persons and instead rely on an embedded network of social relations—in which individuals give without expecting reciprocity from those unable directly to offer the same.

Formal implementation of disability rights will have a limited impact on realizing democratic justice for disabled population in Brazil if the nation's public policies do not also address the continuing oppressive attitudes and norms in the general population toward the impaired and also challenge the status of the country's oligarchic elites. In both Young's and Sen's view, these norms and circumstance undermine the potential for justice and democracy for Brazil's impaired. These points lead me to conclude that without changes in the nation's major economic, social and cultural institutions to boost the standing and effective representation of marginalized groups, the political roles of this population will remain limited. This reasoning helps avoid reducing democratic politics to human rights politics or espousing the mistaken view that formal adoption of a treaty or law ensures its effective implementation or the realization of its aims in democratic politics.

As discussed in Chapter 6, my investigation of relevant disability NGO discourses revealed their broad construction on the basis of liberal conceptions of justice. Advocacy efforts by Brazil's disability NGOs have emphasized individual rights, building on the liberal values of the nation's 1988 Constitution and the UN Convention on the Rights of Persons with Disabilities, such as freedom, equality and autonomy. These organizations appear to operate on the assumption that if the rights of the disabled are guaranteed and their responsibilities appropriately allocated, their full citizenship will be secured and equality and justice achieved across the broader population. This stance in turn poses challenges for efforts

to attain legal, political and social equality and justice for those with severe intellectual and physical impairments. Disability NGOs consider active citizen participation of people with impairments crucial for advancing disability rights and justice, but it should be noted that the participation of these groups in politics is not their responsibility alone. Society at large has long posed attitudinal, communication-related and other barriers that have prevented their participation in political, social and cultural life. Therefore, addressing the long-standing exclusion of people with impairments in society and the prevailing public attitudes that underpin their exclusion is too challenging a task to be left to the individuals or groups with impairments or the disability NGOs alone. Stroman's (2003) account makes clear that social inclusion of the population with impairments is unlikely to occur unless many groups and actors in the nation participate in efforts to secure it, broadening the dialogue in Brazilian society concerning the possibilities of democratic politics.

Finally, Chapter 7 discussed how those Brazilians with impairments I interviewed perceive justice as requiring both distributive elements and equality in social relations. My interviewees articulated conceptions of justice that involved equal opportunity, access, and respect. Wolff (2009) has suggested that addressing equality appropriately entails modifying technology, laws, the built environment and public understanding. People with impairments embraced notions of both personal and collective responsibility for justice in Brazilian society. My interviewees shared their attempts to gain control over their lives and to be independent, which may not be sufficient, as these efforts alone cannot account for the socially constructed perspectives concerning appropriate responsibilities of the broader society, as Wolgast (1987) has argued. Interviewees with impairments acknowledged that solidarity was a critical factor in their collective capacity to address the limitations created by their society's ongoing devotion

to individualism. Those I interviewed expressed a sense of solidarity and the need to dialogue across impairment-related divisions if they were to share responsibility for action to change their collective situation. Unlike other discourses of personal responsibility, which evidenced or implied inferiority due to impairment-related limitations, these respondents seemed to relate to the wider society on more equal terms when they called for dialogue.

To move from these subjective understandings of what justice for the population with impairments entails, the idea of what Hannah Arendt, following Kant, called the “enlarged thought” is helpful (Benhabib, 2003, p. 191). The enlarged thought in Arendt’s view entails bringing different actors together in a moral dialogue with all concerned parties and teaching them how to listen to what is said and to identify when the voices of others are absent or not heard (Benhabib, 1988, p.44). The articulation of the viewpoints of all involved requires as a pre-condition that their civil and political rights are guaranteed, but enlarged thought demands more, the creation of institutions and practices that acknowledge and value a plurality of ideas and actions (Benhabib, 1988, p.47). Young’s (1997) concept of asymmetrical reciprocity helps to consider the importance of difference and plurality. Since each participant in a dialogue is distinguished by a particular history and social position, their relation is asymmetrical, but through dialogue people can understand each other across difference without necessarily reversing perspectives or fully identifying with each other. Dialogue with others may move people from their merely subjective understanding of issues to an enlarged understanding.

One of the examples that Young employed to support her argument was related to the value of the lives of people with impairments among the non-disabled in Oregon. A phone

survey among citizens without impairments in that state revealed that the majority of respondents would prefer to be “dead than wheelchair bound or blind,” and that “their lives would not be worth living if they became disabled” (Young, 1997, p.344). Such opinions lead Oregon state officials to the political decision not to subsidize health services for disabled people in the same way as those for nondisabled people. Clearly, state officials’ judgment lacked input from people with impairments about their health needs in particular and the worth of their lives in general. Soliciting the perspectives of people with impairments may have helped officials make a more informed and deliberative, not to say equitable, decision. Young (1997) has suggested that with careful listening, people without impairments could learn to understand important aspects of the lives and perspectives of their impaired peers, which can significantly augment efforts to occupy their positions empathetically and imaginatively. This is in part because our relationships with others mediate our perspectives and that dialectical process makes it difficult to reverse our positions (Ibid, p.348).

I agree with Young (1997) that the relationship between policymakers, NGOs and people with and without impairments is a mediated one, because, as she has explained, our positions are constituted partly by the perspectives we each have of others. Moreover, each individual and group is enmeshed in relationships of privilege and oppression, and as Young has observed, where relations of privilege and oppression dominate those perspectives, misrepresenting the other’s situation may often be the case (p.349). This was an important consideration as I reflected on the implications of my suggested framework for different stakeholders.

In Chapter 2, I proposed a conception of democratic justice that emerged from analyzing the literature. That effort built on the dialectical relationship between justice and democracy as instrumental and intrinsic, as Young (1990) had suggested. The practice of citizenship is an essential ingredient in a vigorous democracy and Young's account encourages development of public participation and the conditions that support it, affirming group differences and ensuring specific representation for oppressed groups. In this perspective, deliberation implies bringing both state and non-state actors into the discussion and identifying democratic processes with more than one institution or set of institutions. This approach seems attractive as a strategy for addressing social inequality. Gould's (2004) view of the relationship between democracy and human rights as dialectical complements Young's perspective on democracy and justice. Thus, democracy, justice and human rights are linked in both intrinsic and instrumental ways and it is important to act on this more complex understanding of their relationship. Young's approach to justice as a politics of difference places equality at the heart of the concept. Meanwhile, the capabilities approach provides a helpful multidimensional framework to gauge inequalities across different social groups and constitutes a particularly compelling vision for disabled people who have been denied autonomy and dignity and opportunities to develop their potential for many decades around the world.

This framework for understanding democratic justice can serve as a moral touchstone as efforts to secure justice for the impaired in Brazil are pursued via coalition politics. This vision can engage policymakers, citizens, NGOs, businesses, educational institutions and others in developing an enlarged understanding of the issues and relations that is otherwise unavailable to any of them alone (Young, 1997). Democratic justice is broader than individual

rights, yet each of the stakeholders whose views I analyzed offered only a partial view of it. Therefore, identifying what an integrated and more comprehensive account of what conditions might constitute such an outcome for each is an important exercise.

For disability NGOs, policymakers and citizens with and without impairments, democratic justice should start with a humble recognition of the plural experiences and perspectives that constitute social life and of the fact that our viewpoints are in part mediated by our relationships with others. Such a stance may contribute towards increased dialogue and careful listening to learn more about the needs and experiences of others and to provide more avenues for those whose interests might be affected by policy to be heard.

For policymakers, democratic justice will require extending the Brazilian nation's collective understanding of justice beyond policies centered on individual rights and designing institutions and programs instead that encourage widespread grassroots engagement, which entails the encouragement of collective decision-making and broad involvement of citizens and groups concerning diverse political issues that affect them significantly. Brazil's policymakers should also be mindful of the conditions necessary for citizens to enjoy equal social and political status and effective opportunities for participation. Since inequality weakens pursuit of democratic decision-making, as David Held (1996) has contended (p.331), alleviating structural inequality between the most and least powerful is an important aim of democratic justice. But state officials cannot address this goal successfully alone, since citizens, groups and organizations together contribute to the reproduction of structural inequality. Young (2011) is right in suggesting that to be effective, government

policy to promote social justice requires the active and ongoing support of communities (p.112).

Moreover, as I pointed out above, the biomedical model still influences Brazilian society strongly and institutions and policymakers need to be mindful of that fact when crafting policy measures. In addition to encouraging dialogue, public decision-makers need to address the lack of accountability of enacted policies and programs so as to inform stakeholders in their decision-making and action more effectively. Government policies need to incorporate key groups and associations into decision processes and do so in ways consonant with democratic principles, rules and practices.

For disability NGOs, democratic justice will require an understanding of policy implications and their articulation with different civil society, business sector, educational institution and public actors. Division along service provision/advocacy lines needs to be closely scrutinized, rather than accepted by default. Disability NGOs also need to collaborate with other organizations on issues beyond impairment and disability, which will encourage the various identity groups to share perspectives, understand one another's positions more deeply and collaborate more effectively. Partnering with educational institutions to encourage more research interest in a host of issues related to impairment and disability will help bring scholars and practitioners together to inform both theory development and exploration and the possibility of praxis.

It is clear that democratic justice for citizens with and without impairments needs to be attained and sustained at the grassroots level. As many of my interviewees noted, the more opportunities for coexistence members of society have, the more they will come together

around common passions, purposes and projects and the easier the goal of equality and respect will be to address over time. There is also much activist experience and history on which to draw in Brazil that can be shared with younger generations of individuals with impairments. It is important not only to keep youths engaged, but also to make them aware of the struggle for civil and human rights so that hard-won progress and social legitimacy and standing do not end up being treated as possessions guaranteed only by recent policies.

### **Implications for Further Research**

There is no single uniform understanding of what justice for Brazilians with impairments means and this study has attempted to sketch a conception of what conditions might constitute justice for the nation's citizens with impairments. This understanding can surely be deepened by further research that addresses several limitations of this study, a concern to which I now turn.

First, learning more about the effects of specific policies on the lives of people with impairments would be beneficial. One potential strategy for accomplishing this step could be cooperating with local universities and research centers to collect quantitative data through surveys and qualitative data through interviews and participant observation for a larger sample, targeting both policymakers and those affected by those individuals' efforts.

Second, I regret not being able to represent the population with impairments from across all of Brazil in the present study, but this lacuna can be addressed in future work and doing so might reveal regional differences. Examining disability and justice discourses across legal and policy actions for other localities, or in specific sub-groups, can also be tackled

through additional inquiry in other urban and rural settings across Brazil and Latin America. Empirically investigated questions in the setting of a particular time and place, such as how the specifics of gender, race and sexuality affect the lives of people with impairments, will help reveal socially and policy significant differences in oppression and power among this population.

Third, inclusion of people with impairments in society depends not only on supportive policies, but also strongly on existing culture. The arts and culture can be not only objects of study, but also methods and approaches themselves that help advance social justice. I see investigating the role of culture and the arts in advancing justice and disability rights as holding significant potential. Some studies position the arts as an alternative to more conventional modes of analytic discussion, drawing on symbolic references to communicate nonverbally perceptions or perspectives concerning lived experiences that are often missed when communicating through words alone (Shank & Schirch, 2008, p.14). By focusing on human relations, emotions and narratives the arts can help populations change negative attitudes in a society towards impairment and disability, as well as re-imagine the world and people's co-existence in it. There is a growing body of scholarship that argues for the positive impact of arts-based approaches for social change, and disability scholarship may benefit from those efforts.

Fourth, further study could explore the potential for entrepreneurship by people with impairments. While in the United States entrepreneurs with disabilities are almost twice as likely as individuals without impairments to start a business,<sup>116</sup> and many public and private sector organizations support them, including Small Business Development Centers,<sup>117</sup> other

government programs, community and faith-based organizations and business incubators, this assistance is lacking in developing countries. In Brazil, universities play key a role in the country's entrepreneurial and innovation ecosystem through educational curricula and start-up programs. Brazil's incubator network totaled 400 sites in 2007, making it one of the most successful of such initiatives in Latin America (Chandra, 2007). However, youths with impairments are significantly under-represented in universities and therefore this resource is largely unavailable to them.

I hope this dissertation will serve in a modest way to engage Brazil's policy-makers, disability rights advocates, scholars and people with and without impairments in a dialogue about the meanings of justice and the implications of those perspectives for policy arguments and for social change. While some may not agree with the interpretations and conclusions expressed in this study, I believe the understanding of justice developed here may start a fruitful dialogue and potentially be helpful for addressing social and political issues faced by other oppressed and marginalized populations. If we are to attempt to realize democratic justice, we must press ahead in many ways to learn the needs and views of those who have been the traditional targets of social discrimination. That goal is no less compelling for Brazil as for nations across the globe.

## Endnotes

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<sup>1</sup> The works of Brazilian scholars, ranging from Anthropology, Political Science, to Social Service and Nursing, have been accessed through the Brazilian Digital Library of Theses and Dissertations, supported by the Brazilian Ministry of Science and Technology. A number of works have been accessed at <http://bdtd.ibict.br/en/inicio.html>, on June 8, 2010, utilizing search words “deficiencia” (disability), “justiça social” (social justice) and “direitos” (rights).

<sup>2</sup> Conrad defines medicalization as follows: “Medicalization consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to ‘treat’ it” (Conrad, 1992, p.211). He observes that the interest in medicalization has predominantly focused on the medicalization of previously nonmedical problems, which often occurred inappropriately, when, for example, disability was viewed as illness or disorder rather than political category.

<sup>3</sup> See, for example, a book published by Debora Diniz in 2007 that takes a feminist perspective in criticizing the medical model and praising the social model of disability in *O que é deficiência?* [What is disability?]; Reicher & Atalla, 2011.

<sup>4</sup> See, for example, the dissertation of cultural anthropologist Pamela Block who in 1997 addressed the influence of cultural beliefs and professional theories in cognitive disability in “Biology, Culture and Cognitive Disability: Twentieth Century Professional Discourse in Brazil and the United States.” Doctoral Dissertation, Duke University.

<sup>5</sup> Portions of this section appeared in Kirakosyan, 2012.

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<sup>6</sup> Brazil had a brief period of representative democracy in 1950-1964, when citizens elected their representatives and president and enjoyed a free press (Levine, 1999, pp.15-16). The subsequent military dictatorship lasted two decades, Brazil undertook the road to democratization road in the second half of the 1980s.

<sup>7</sup> Brazil has had seven Constitutions: 1824, 1891, 1934, 1937, 1946, 1967 and 1988. The 1988 Constitution replaced the authoritarian 1967 Constitution, which made some fundamental rights relative: the loss of political rights for two to ten years was instituted for practicing freedom of thought, freedom of work, freedom of meeting and freedom of association. Based on this article, many were arrested for charges of "conspiracy against the democratic order." The militaries issuing Institutional Acts, which could not be amended by the Parliament; when members of Parliament became more vocal against the dictatorship, the militaries shut the legislature down.

<sup>8</sup> The Constitution of the Federal Republic is based on five fundamental principles: sovereignty, citizenship, human dignity, social value of work and free initiative, and political pluralism. See the Constitution of Brazil, compiled amendments, 2008. Available at [http://www.planalto.gov.br/ccivil\\_03/constituicao/constitui%C3%A7ao.htm](http://www.planalto.gov.br/ccivil_03/constituicao/constitui%C3%A7ao.htm). The translation of this text as well as other referenced works from Portuguese to English is mine.

<sup>9</sup> If Congress fails to act on a provisional decree within 30 days, it automatically goes to the top of the legislative agenda, displacing issues that the legislature may have been discussing. According to the Constitution, a provisional decree should only be used in specific situations,

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although in practice the Executive has made indiscriminate use of this device. A large number of provisional decrees been edited in past legislatures.

<sup>10</sup> Personal Interview with disability NGO leader, conducted on August 17, 2011.

<sup>11</sup> Retrieved on July 1<sup>st</sup>, 2012 from

<http://www.mds.gov.br/brasilsemmiseria/arquivos/BSM.pdf>

<sup>12</sup> Retrieved from Federal Government's Blog <http://blog.planalto.gov.br/governo-lanca-plano-nacional-dos-direitos-da-pessoa-com-deficiencia/>

<sup>13</sup> Personal interview with disability NGO leader, conducted July 14, 2011.

<sup>14</sup> I retrieved the WHO factsheet from

[http://www.who.int/disabilities/world\\_report/2011/factsheet.pdf](http://www.who.int/disabilities/world_report/2011/factsheet.pdf).

<sup>15</sup> UN Factsheet on Persons with Disabilities, retrieved from

<http://www.un.org/disabilities/default.asp?id=18> .

<sup>16</sup> Personal Interview with disability NGO leader, conducted August 11, 2011.

<sup>17</sup> I retrieved the survey from <http://www.ibdd.org.br/>

[noticias/noticiaspesquisa%20data%20senado%20ibdd.asp](http://www.ibdd.org.br/noticias/noticiaspesquisa%20data%20senado%20ibdd.asp).

<sup>18</sup> Source: Survey conducted by Senate and IBDD. Pollsters talked to 1,165 people with various disabilities, except for intellectual impairments. Details available at

<http://www.ibdd.org.br/arquivos/Apresentacao%20Pesquisa%20Pessoa%20com%20Deficiencia.pdf>

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<sup>19</sup> Personal interview with disability NGO leader, conducted August 11, 2011.

<sup>20</sup> General characteristics of population from 2010 Census retrieved from

[http://www.ibge.gov.br/home/presidencia/noticias/noticia\\_impressao.php?id\\_noticia=2170](http://www.ibge.gov.br/home/presidencia/noticias/noticia_impressao.php?id_noticia=2170)

<sup>21</sup> The summary of 2010 Census was retrieved from

[http://www.ibge.gov.br/home/presidencia/noticias/noticia\\_visualiza.php?id\\_noticia=2125&id\\_pagina=1](http://www.ibge.gov.br/home/presidencia/noticias/noticia_visualiza.php?id_noticia=2125&id_pagina=1)

<sup>22</sup> General characteristics of population from 2010 Census retrieved from

[http://www.ibge.gov.br/home/presidencia/noticias/noticia\\_impressao.php?id\\_noticia=2170](http://www.ibge.gov.br/home/presidencia/noticias/noticia_impressao.php?id_noticia=2170)

<sup>23</sup> The survey was conducted by i.Social in the beginning of 2012 involving 674 adults with impairments across Brazil. Retrieved from

[http://www.isocial.com.br/download/deficiencia\\_relatorio-2012.pdf](http://www.isocial.com.br/download/deficiencia_relatorio-2012.pdf) on June 10, 2012.

<sup>24</sup> The proposed law 105/08 was in the Senate in the process of review and approval since March 2008, and in July 2011 was returned for the final review by the lawmakers, according to the Senate's website. Retrieved from

[http://www.senado.gov.br/atividade/materia/detalhes.asp?p\\_cod\\_mate=84392](http://www.senado.gov.br/atividade/materia/detalhes.asp?p_cod_mate=84392)

<sup>25</sup> Global Entrepreneurship Monitor. GEM Brazil 2010 National Report, available at

<http://www.gemconsortium.org/document.aspx?id=1131> ; accessed September 19, 2011

<sup>26</sup> <http://www.livroacessivel.org/blog/tag/censo-escolar-2010/> accessed December 1st, 2011

<sup>27</sup> Personal Interview with disability NGO leader, conducted July 27, 2011.

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<sup>28</sup> Retrieved from <http://www.fomezero.gov.br/noticias/falta-de-escolarizacao-exclui-pessoas-com-deficiencia-do-mercado-de-trabalho-diz-conade/?searchterm=BPC%20deficiencia>

<sup>29</sup> Personal interview conducted on July 26, 2011.

<sup>30</sup> According to traffic safety specialists, attackers target the most fragile individuals.

Retrieved from <http://estilo.br.msn.com/tempodemulher/dicas/mulheres-ainda-s%C3%A3o-as-principais-v%C3%ADtimas-de-assalto-no-tr%C3%A2nsito-diz-especialista>

<sup>31</sup> The UN Factsheet on Persons with Disabilities reviews key statistics available worldwide concerning living conditions of this population, including education, employment and violence. Retrieved from <http://www.un.org/disabilities/default.asp?id=18> .

<sup>32</sup> Position paper of the International Disability Alliance, IDA, on the UN Convention. The paper provided guidance on particular areas in which the Convention superseded earlier standards articulated by the UN, 2008. Retrieved December 7, 2011 from [www.un.org/disabilities/documents/COP/IDA%20CRPD%20paper.doc](http://www.un.org/disabilities/documents/COP/IDA%20CRPD%20paper.doc). IDA is a prominent international disability advocacy organization that claims to represent the interests of more than one billion disabled people worldwide by promoting, “the effective and full implementation of the UN Convention on the Rights of Persons with Disabilities worldwide, as well as compliance with the CRPD within the UN system, through the active and coordinated involvement of representative organisations of persons with disabilities at national, regional and international levels.”

<sup>33</sup> Ibid

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<sup>34</sup> According to the UN, as of May 31, 2012, the CRPD had been signed by 153 states and its Optional protocol by 90 states. After signing the Convention, the individual states need to put the document through their national legislative process to ratify it. As of May 2012, 113 states had ratified the Convention and 65 its Optional protocol. Retrieved from [http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&lang=en](http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en). and <http://www.un.org/disabilities/countries.asp?id=166>.

<sup>35</sup> Frequently Asked Questions regarding the Convention on the Rights of Persons with Disabilities, ‘Why is the Convention unique?’ Retrieved from <http://www.un.org/disabilities/default.asp?navid=24&pid=151>

<sup>36</sup> Personal Interview with a disability NGO leader, conducted on August 17, 2011.

<sup>37</sup> The Commissioner for Human Rights of the Council of Europe commissioned and published a series of Issue papers elaborated by experts to contribute to debate and reflection on important current human rights issues. This particular debate refers to the right to legal capacity for persons with intellectual and psychosocial disabilities (Art.12 of the CRPD). Retrieved from <https://wcd.coe.int/ViewDoc.jsp?id=1908555>.

<sup>38</sup> The Convention defined “Persons with disabilities” in Article 1 as follows: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN 2006), retrieved from [www.un.org/disabilities/default.asp?id=151](http://www.un.org/disabilities/default.asp?id=151).

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<sup>39</sup> In a nutshell, first generation rights were set out in the Universal Declaration of Human Rights of 1948, dealing with civil and political rights, and asserting dignity, equality, and integrity of the person. The second category involves economic, social and cultural rights. The third generation of human rights relates to collective, environmental, and development rights. (Adapted from Evans, 2008).

<sup>40</sup> The most recent National Census in Brazil was conducted in 2010, and the responsible governmental organ, National Institute of Geography and Statistics - IBGE, collected data on the population with impairments by sampling households. Although some activists filed complaints against this practice before the Census started, demanding an actual headcount instead of sampling, its preparations were at the advanced stage and could not be altered.

<sup>41</sup> The news on Brazil submitting its first progress report on the implementation of the CRPD was published on the website of the Secretariat of Human Rights (<http://www.direitoshumanos.gov.br>) on May 30, 2012. However, the report hasn't been available on the Internet to consult its final version.

<sup>42</sup> At the Civil Society Forum regarding CRPD that took place during the Fifth Conference of the State Parties to CRPD in September 2012, Permanent Representative of Sweden to the UN, his Excellency Martin Grunditz commented on the comparative disadvantage of the CRPD Committee next to other UN human rights-related conventions. According to H.E. Grunditz, the CRPD Committee meets only three weeks a year to service 119 signatory states, while other committees on human rights-related conventions meet around nine weeks a year to service on average 170 state members. H.E. Grunditz called for the need for necessary adjustments by the UN General Assembly, namely to prolong the CRPD Committee meeting

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period. The Committee needs to review the individual country reports on fulfillment of the provisions of the Convention, and analyze specific cases. If the adjustment is not made, H.E. Grunditz feared that the reports and cases will pile up, creating frustration not only among party states, but also among the rights holders themselves. The Forum's webcast was retrieved from <http://bcove.me/htlq413y> .

<sup>43</sup> A short version of this section appeared in Kirakosyan, 2012.

<sup>44</sup> Personal Interview with a disability NGO leader, conducted on August 17, 2011.

<sup>45</sup> Personal Interview with a disability NGO leader, conducted on July 12, 2011.

<sup>46</sup> Personal Interview with a disability NGO leader, conducted on August 17, 2011.

<sup>47</sup> Personal Interview with a disability NGO leader, conducted on July 14, 2011.

<sup>48</sup> Personal Interview with a disability NGO leader, conducted on July 14, 2011.

<sup>49</sup> Personal Interview with a disability NGO leader, conducted on August 2, 2011.

<sup>50</sup> Personal interview with a disability NGO leader, conducted on July 14, 2011.

<sup>51</sup> The National Report, both in General and Specific parts, is available for download at <http://www.pessoacomdeficiencia.gov.br/app/relatorio-de-monitoramento-da-convencao>.

<sup>52</sup> RAIS 2010 reported that formally employed disabled women, on average, earned only seventy percent of what disabled men earned in 2010. RAIS is an Annual Survey of Social Information, gathered and published by the Brazilian government. Retrieved from [www.rais.gov.br](http://www.rais.gov.br).

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<sup>53</sup> In the realm of education, the CRPD's objective is to ensure development of children with impairments to their 'fullest potential' (Art.24b), which contrasts with the National Education Plan 2011-2020 (Plano Nacional de Educação 2011-2020) that focuses on access and inclusion of these children in the regular classes at schools. The National Education Plan was finally approved by the Brazilian legislature in June 2012, after 18 months of consideration.

<sup>54</sup> A short version of this section appeared in Kirakosyan, 2012.

<sup>55</sup> Personal Interview with a disability NGO leader, conducted on August 17, 2011.

<sup>56</sup> I reviewed the websites of such organizations as: 3IN, AACD, ABRASC, ADEVA, ADID, AHIMSA, AVAPE, CVI Brasil, Escola de Gente, FENAPAE, IBDD, Instituto Paradigma, Laramara, Mais Diferencas, RIADIS, and Vida Brasil.

<sup>57</sup> Personal Interview with a disability NGO leader, conducted on August 11, 2011.

<sup>58</sup> Personal Interview with a disability NGO leader, conducted on July 12, 2011.

<sup>59</sup> Personal Interview with a disability NGO leader, conducted on July 27, 2011.

<sup>60</sup> The report published in the Brazilian business magazine *Exame* in 2008 analyzed the recent trends identified in the nonprofit sector as the entities adopt more and more business practices – competition, efficiency, cost-effectiveness, etc. The report stated that the majority of the 300,000 NGOs operating in Brazil lack basic financial management processes and suffer from inefficiency. This impacts their ability to fundraise and sustain their operations. Retrieved from [http://planetasustentavel.abril.com.br/noticia/desenvolvimento/conteudo\\_281591.shtml](http://planetasustentavel.abril.com.br/noticia/desenvolvimento/conteudo_281591.shtml)

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<sup>61</sup> I was able to obtain and study institutional / annual reports of the following organizations:

Nosso Lar, Instituto Paradigma, Mais Diferenças, and IBDD.

<sup>62</sup> I reviewed the websites of such organizations as 3IN (Inclusion, Integrity, Independence, [www.3in.org.br](http://www.3in.org.br)), AACD (Association for the Assistance to the Disabled Child, [www.aacd.org.br](http://www.aacd.org.br)), ABEM (Brazilian Association of Multiple Sclerosis, [www.abem.org.br](http://www.abem.org.br)), ADEVA (Association of Visually Impaired and their Friends, [www.adeva.org.br](http://www.adeva.org.br)), ADID (Association for the Integral Development of Persons with Down Syndrome, [www.adid.org.br](http://www.adid.org.br)), AHIMSA (Educational Association for Deafblind, [www.ahimsa.org.br](http://www.ahimsa.org.br)), AVAPE (Association for appreciation of persons with disability, [www.avape.org.br](http://www.avape.org.br)), CVI-Brasil (Center for Independent Life – Brazil, [www.cvi.org.br](http://www.cvi.org.br)), Escola de Gente (People’s School, [www.escoladegente.org.br](http://www.escoladegente.org.br)), FENAPAE (National Federation of the Associations of Parents and Friends of Exceptionals, [www.apaebrasil.org.br](http://www.apaebrasil.org.br)), IBDD (Brazilian Institute for the Rights of Persons with Disability, [www.ibdd.org.br](http://www.ibdd.org.br)), Instituto Paradigma ([www.institutoparadigma.org.br](http://www.institutoparadigma.org.br)), Laramara (Brazilian Association of the Assistance to the Visually Impaired, [www.laramara.org.br](http://www.laramara.org.br)), Mais Diferenças (More Differences, [www.md.org.br](http://www.md.org.br)), RIADIS (Latin American Network of NGOs of people with disability and their families, [www.riadis.net](http://www.riadis.net)), and Vida Brasil (Appreciation of the Individual and his active development, [www.vidabrasil.org.br](http://www.vidabrasil.org.br)).

<sup>63</sup> Retrieved from <http://www.fundacaodorina.org.br/o-que-fazemos/livros-acessiveis/>

<sup>64</sup> Retrieved from [www.laramara.org.br](http://www.laramara.org.br)

<sup>65</sup> Retrieved from <http://www.abraso.org.br/instituicao.html>

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<sup>66</sup> Retrieved from [www.avape.org.br](http://www.avape.org.br)

<sup>67</sup> Retrieved from <http://www.oncb.org.br>

<sup>68</sup> Personal Interview with a disability NGO leader, conducted on August 11, 2011.

<sup>69</sup> Personal Interview with a disability NGO leader, conducted on August 11, 2011.

<sup>70</sup> Personal Interview with a disability NGO leader, conducted on July 14, 2011.

<sup>71</sup> Personal Interview with a disability NGO leader, conducted on July 26, 2011.

<sup>72</sup> The emergence of APAEs – Associações de Pais e Amigos dos Excepcionais (Associations of Parents and Friends of Exceptionals) in the 1950s had its roots as local self-help groups. Today 2,000 of these associations are united in APAE Federation present in 23 out of 26 states in Brazil, involved in disability rights advocacy and service provision for people with intellectual impairments. Retrieved from

<http://www.apaesaopaulo.org.br/arquivos.phtml?t=12122>

<sup>73</sup> Retrieved from <http://www.vidabrasil.org.br/>

<sup>74</sup> Retrieved from <http://www.riadis.org/observatorio/en/conocer-la-riadias/#.URCPxaXhpR0>

<sup>75</sup> Personal Interview with a disability NGO leader, conducted July 12, 2011.

<sup>76</sup> Personal Interview with a disability NGO leader, conducted on July 12, 2011.

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<sup>77</sup> The survey was conducted by *i.Social* in the beginning of 2012 involving 674 adults with impairments across Brazil. Retrieved from

[http://www.isocial.com.br/download/deficiencia\\_relatorio-2012.pdf](http://www.isocial.com.br/download/deficiencia_relatorio-2012.pdf) on June 10, 2012.

<sup>78</sup> Personal Interview with a disability NGO leader, conducted on August 11, 2011.

<sup>79</sup> Personal Interview with a disability NGO leader, conducted on August 17, 2011.

<sup>80</sup> Personal Interview with a disability NGO leader, conducted in July 12, 2011.

<sup>81</sup> Personal Interview with a disability NGO leader, conducted on July 14, 2011.

<sup>82</sup> Personal Interview with a disability NGO leader, conducted on July 12, 2011.

<sup>83</sup> The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains, classified from body, individual (body functions) and societal perspectives (participation). The ICF includes a list of environmental factors, to consider an individual's functioning and disability in a context. The ICF is the World Health Organization's (WHO) framework for measuring health and disability at both individual and population levels. All 191 WHO Member States officially endorsed it in the 44<sup>th</sup> World Health Assembly on 22 May 2001. Retrieved from World Health Organization's website <http://www.who.int/classifications/icf/en/>

<sup>84</sup> Personal interview conducted on July 20, 2011.

<sup>85</sup> Personal interview conducted on July 29, 2011.

<sup>86</sup> Personal interview conducted on July 27, 2011

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<sup>87</sup> Personal interview conducted on July 26, 2011.

<sup>88</sup> Personal interview conducted on July 20, 2011.

<sup>89</sup> Personal interview conducted on July 5, 2011.

<sup>90</sup> Personal interview conducted on July 20, 2011.

<sup>91</sup> Personal interview conducted on July 26, 2011.

<sup>92</sup> Personal interview conducted on July 05, 2011.

<sup>93</sup> Personal interview conducted on July 28, 2011.

<sup>94</sup> Personal interview conducted on August 09, 2011.

<sup>95</sup> Personal interview conducted on July 29, 2011.

<sup>96</sup> Personal interview conducted on July 26, 2011.

<sup>97</sup> Personal interview conducted on July 26, 2011.

<sup>98</sup> Personal interview conducted on July 26, 2011.

<sup>99</sup> Personal interview conducted on July 29, 2011.

<sup>100</sup> Personal interview conducted on July 26, 2011.

<sup>101</sup> Personal interview conducted on August 13, 2011.

<sup>102</sup> Personal interview conducted on July 26, 2011.

<sup>103</sup> Personal interview conducted on July 29, 2011.

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<sup>104</sup> Personal interview conducted on July 20, 2011.

<sup>105</sup> Personal interview conducted on July 20, 2011.

<sup>106</sup> Personal interview conducted on August 09, 2011.

<sup>107</sup> Personal interview conducted on August 09, 2011.

<sup>108</sup> Personal interview conducted on July 28, 2011.

<sup>109</sup> Personal interview conducted on July 27, 2011.

<sup>110</sup> Personal interview conducted on July 26, 2011.

<sup>111</sup> Personal interview conducted on July 20, 2011.

<sup>112</sup> Personal interview conducted on July 29, 2011.

<sup>113</sup> Personal interview conducted on July 20, 2011.

<sup>114</sup> Anita Silvers (2009) drew on Minow's analysis of difference that established how law and policy affect diverse populations through the legal framing of difference. This discussion called for a reconceptualization of difference to advance justice, a call that Silvers embraced. She concluded that cooperation among diverse actors, without ranking who tops the list in escaping disadvantage, holds better prospects for including all kinds of difference in society (Silvers, 2009).

<sup>115</sup> Personal interview with a disability NGO leader, conducted on July 26, 2011.

<sup>116</sup> Retrieved from <http://www.dol.gov/odep/pubs/misc/entrepre.htm>

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<sup>117</sup> Small Business Development Centers (SBDCs) are partnerships established between the government and colleges/universities administered by the Small Business Administration. The program provides educational services for small business owners and aspiring entrepreneurs.

Source: [www.sba.gov](http://www.sba.gov).

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# Appendix A

## IRB Approval & Extension Letters



VirginiaTech

Office of Research Compliance  
Institutional Review Board  
2000 Kraft Drive, Suite 2000 (0497)  
Blacksburg, Virginia 24060  
540/231-4606 Fax 540/231-0959  
e-mail [irb@vt.edu](mailto:irb@vt.edu)  
Website: [www.irb.vt.edu](http://www.irb.vt.edu)

### MEMORANDUM

DATE: June 20, 2011

TO: Max O. Stephenson, Lyusyena Kirakosyan

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires May 31, 2014)

PROTOCOL TITLE: Social Justice for the People with Disabilities in Brazil: Legal, Political, and Moral Discourses

IRB NUMBER: 11-382

Effective June 13, 2011, the Virginia Tech Institutional Review Board, at a convened meeting, approved the new protocol for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at <http://www.irb.vt.edu/pages/responsibilities.htm> (please review before the commencement of your research).

### PROTOCOL INFORMATION:

Approved as: Full Board Review

Protocol Approval Date: 6/13/2011

Protocol Expiration Date: 6/12/2012

Continuing Review Due Date\*: 4/30/2012

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

### FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals / work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

*Invent the Future*

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY  
*An equal opportunity, affirmative action institution*



**MEMORANDUM**

**DATE:** May 14, 2012  
**TO:** Max O Stephenson Jr, Lyusyena H Kirakosyan  
**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires May 31, 2014)  
**PROTOCOL TITLE:** Social Justice for the People with Disabilities in Brazil: Legal, Political and Moral Discourses  
**IRB NUMBER:** 11-382

Effective May 14, 2012, the Virginia Tech Institutional Review Board (IRB) Administrator, Carmen T Green, approved the Continuing Review request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

<http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

**PROTOCOL INFORMATION:**

Approved As: **Full Review**  
Protocol Approval Date: **June 13, 2012**  
Protocol Expiration Date: **June 12, 2013**  
Continuing Review Due Date\*: **May 29, 2013**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

**FEDERALLY FUNDED RESEARCH REQUIREMENTS:**

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

*Invent the Future*

Date*	OSP Number	Sponsor	Grant Comparison Conducted?

\* Date this proposal number was compared, assessed as not requiring comparison, or comparison information was revised.

If this IRB protocol is to cover any other grant proposals, please contact the IRB office (Irbadmin@vt.edu) immediately.

## **Appendix B**

### **List of sample interview questions: disability NGO leaders**

These interview questions have been designed to explore the foundational concepts of justice on which disability NGOs predicate their claims. I will use questions very similar to those that appear below in my proposed interviews.

1. What is (are) the meaning(s) of the UN Convention for the Rights of People with Disabilities for your organization, for other advocacy organizations (as you understand those), for Brazilians with disabilities and for Brazilian society in general? Could you share some stories or examples that illustrate these meanings for each group?
2. Your advocacy organization participated in the process of crafting and negotiating the UN Convention (and /or your organization has been active in its promotion with Brazilian legislators). What has your NGO done specifically since the Convention's adoption in Brazil to promote the just and fair treatment of individuals with disabilities? How would you personally and your organization define just and fair?
3. Based on your experience and knowledge, do you think disability advocacy NGOs in Brazil represent the perceived interests of people with disabilities in a just and fair way?
4. In your view, is justice for people with disabilities different from justice for people without disabilities? Do you agree that both people with and without disabilities should possess equal rights? Or, would you argue that people with disabilities are entitled to different rights compared to people without disabilities? If this is your view, can you explain the differences for me?
5. Can you share with me your experience with Brazilian public policies for people with disabilities? Based on your knowledge and involvement do you think they are just? Why or why not and in what respects?
6. As a civil society organization, what has been your experience as your organization has sought to establish partnerships with government to promote the rights of people with disabilities?
7. In your view, how just is Brazilian society in general and for the disabled in particular? What would you change, if anything, in Brazilian society to make it more just for the disabled? If you believe change is necessary to secure justice generally and/or for the disabled, can you identify for me what you take to be the root of the problem?
8. How do you imagine the future will unfold for Brazilians with disabilities— say, 10-20 years from now? What issues do you think they (as a population) may confront? How do you think

social policies and attitudes might have changed and why? Do you see disability advocacy NGO's roles and missions changing in the coming two decades? If so, how?

9. How do you feel about participating in this study and reflecting on justice issues concerning people with disabilities in Brazil?
10. Is there anything I have not asked that strikes you as important about this issue? Are there any related stories or concerns you would like to share that will help me to understand better your views on the issues we have discussed?

### **Lista de perguntas para uma entrevista com os líderes das ONGs de causa de deficiência**

Estas perguntas de entrevista foram desenvolvidas para explorar os conceitos fundamentais de justiça com base em quais as ONGs de advocacy que trabalham com deficiência formam suas reivindicações.

1. Qual é (são) o(s) significado(s) da Convenção da ONU de Direitos das Pessoas com Deficiência para sua organização, para outras ONGs de advocacy (ao seu entender), para os brasileiros com deficiência e para a sociedade brasileira em geral? Poderia compartilhar algumas histórias ou exemplos que ilustram estes significados para cada grupo?
2. A sua organização de advocacy participou em processo de discussão e negociação da Convenção da ONU (e/ou a sua organização foi ativa na promoção da Convenção da ONU com os legisladores brasileiros). O que a sua organização tem feito desde a ratificação da Convenção no Brasil para promover os direitos para as pessoas com deficiência? Como o(a) Sr.(a) e a sua organização definem o que é justo?
3. Baseado em sua experiência e conhecimento, o(a) Sr.(a) pensa que as ONGs de advocacy que trabalham com deficiência no Brasil representam os interesses das pessoas com deficiência de uma maneira justa?
4. Ao seu ver, a justiça para as pessoas com deficiência seria diferente da justiça para as pessoas sem deficiência? O(A) Sr.(a) concorda que ambas as pessoas com e sem deficiência deveriam possuir direitos iguais? Ou contrário, o(a) Sr.(a) defenderia que as pessoas com deficiência deveriam ter direitos diferentes comparando com as pessoas sem deficiência? Se o ultimo for a sua visão, poderia explicar as diferenças para mim?
5. O(A) Sr.(a) poderia compartilhar comigo a sua experiência com as políticas públicas em relação às pessoas com deficiência? Baseado em seu conhecimento e envolvimento, O(A) Sr.(a) acha elas justas? Porquê sim ou não?
6. Como uma organização de sociedade civil, qual é a sua experiência em estabelecer parcerias com governo na promoção de direitos das pessoas com deficiência?

7. Ao ser ver, quão justa é a sociedade brasileira em geral e para as pessoas com deficiência em particular? Se for mudar algo, o que seria, para fazer a sociedade brasileira mais justa? Se o(a) Sr.(a) acredita na necessidade de transformação social para assegurar justiça na sociedade em geral e para as pessoas com deficiência, poderia identificar qual é a raiz do problema?
8. Como o(a) Sr.(a) imagina o futuro para as pessoas com deficiência no Brasil, digamos daqui a 10-20 anos? Que questões elas como população irão enfrentar, ao seu ver? Como o(a) Sr.(a) vê as políticas sociais e atitudes se mudando e porquê? Como o(a) Sr.(a) vê os papéis e as missões das ONGs de advocacy que trabalham com deficiência se mudando?
9. Como se sente em relação à sua participação nesta pesquisa e a sua reflexão sobre os assuntos de justiça para as pessoas com deficiência no Brasil?

Tem alguma questão sobre este assunto que não lhe perguntei, mas o(a) Sr.(a) acha importante? O(A) Sr.(a) teria algumas histórias, exemplos ou preocupações que gostaria de compartilhar para me ajudar a entender a sua posição sobre as questões discutidos?

## Appendix C

### List of sample interview questions: individuals with impairments

These interview questions have been designed to explore the understandings and experiences of Brazilians with impairment as they relate to justice. I will ask questions very like those below as I conduct these interviews.

1. What is your experience as a person with disability in terms of living in the city of São Paulo? Would you share some stories?
  - In terms of accessible infrastructure (schools, streets, transportation, hospitals, etc.)?
  - how ordinary individuals respond with interacting with someone with disabilities?
  - In terms of your rights according to public policies in place?
2. How do you see the equality between people with and without disabilities? Do you believe a person without disability can understand the situation and (in)justice confronted by a person with disabilities? Do you believe a person with disability can understand the situation and (in)justice issues of another person with a disability? How do you feel about participating in this study and reflecting on justice issues concerning people with disabilities in Brazil?
3. How do you imagine justice for people with disabilities? Is it different from justice for people without disabilities? Do you agree that both people with and without disabilities should possess equal rights? Or, would you argue that people with disabilities are entitled to different rights compared with people without disabilities?
4. What would you change in Brazilian society to make it more just? Assuming you have concerns, can you identify the root of the problem that creates injustice? Do you believe the current situation needs to be changed?
5. What is your experience with Brazilian public policies for people with disabilities? From what you know, do you think they are just? Why or why not and in what respects?
6. Do you follow legislative changes regarding people with disabilities? Where and how (print media, TV, friends, colleagues, etc.)? From what you know, what is your perception of legislators' projects in terms of justice?
7. Do you have any experience with NGOs that work to promote the rights of people with disabilities? What do you think about their work? Do you think they represent the claims of people with disabilities in a just and fair way?
8. How do you imagine the future of Brazilians with disabilities— 10-20 years from now?

9. Is there anything I have not asked that strikes you as important about this issue? Are there any related stories you would like to share?

### **Lista de Perguntas para uma Entrevista com as Pessoas com Deficiência**

Estas perguntas de entrevista foram desenvolvidas para explorar os entendimentos e as experiências dos Brasileiros com deficiência em relação à justiça e normas vigentes.

1. Qual é a sua experiência como uma pessoa com deficiência que mora em São Paulo? Poderia compartilhar algumas histórias?
  - Em termos de infra-estrutura acessível (escolas, ruas, transportes, etc)?
  - Como as pessoas reagem na interação com alguém com deficiência?
  - Em termos de seus direitos assegurados na política pública vigente?
2. Como o(a) Sr.(a) vê a igualdade entre as pessoas com e sem deficiência? Acredita que uma pessoa sem deficiência poderia entender a situação e a injustiça enfrentada por uma pessoa com deficiência? Acredita que uma pessoa com deficiência poderia entender a situação e a injustiça enfrentada por uma outra pessoa com deficiência? Como se sente de participar nesta pesquisa e refletir nas questões de justiça em relação às pessoas com deficiência no Brasil?
3. Como imagina a justiça para as pessoas com deficiência? Ao seu ver, a justiça para as pessoas com deficiência seria diferente da justiça para as pessoas sem deficiência? O(A) Sr.(a) concorda que ambas as pessoas (com e sem deficiência) deveriam possuir direitos iguais? Ou ao contrário, o(a) Sr.(a) defenderia que as pessoas com deficiência deveriam ter direitos diferentes comparando com as pessoas sem deficiência? Poderia explicar as diferenças para mim?
4. Ao ser ver, quão justa é a sociedade brasileira em geral e para as pessoas com deficiência em particular? Se for mudar algo, o que seria, para fazer a sociedade brasileira mais justa? Se o(a) Sr.(a) acredita na necessidade de transformação social para assegurar justiça na sociedade em geral e para as pessoas com deficiência, poderia identificar qual é a raiz do problema?
5. O(A) Sr.(a) poderia compartilhar comigo a sua experiência com as políticas públicas em relação às pessoas com deficiência? Baseado em seu conhecimento e envolvimento, O(A) Sr.(a) acha elas justas? Porquê sim ou não?

6. O(A) Sr.(a) acompanha os avanços na legislação em relação às pessoas com deficiência? Aonde e como (mídia impressa, TV, amigos, colegas, etc)? Baseado em seu conhecimento, qual é a sua percepção dos projetos dos legisladores serem justos?
7. O(A) Sr.(a) tem alguma experiência com as ONGs que promovem os direitos das pessoas com deficiência? O que acha do trabalho delas? O(A) Sr.(a) acha que elas representam as reivindicações das pessoas com deficiência de uma maneira justa?
8. Como o(a) Sr.(a) imagina o futuro para as pessoas com deficiência no Brasil, digamos daqui a 10-20 anos?
9. Tem alguma questão sobre este assunto que não lhe perguntei, mas o(a) Sr.(a) acha importante? O(A) Sr.(a) teria algumas histórias, exemplos ou preocupações que gostaria de compartilhar para me ajudar a entender a sua posição sobre as questões discutidos?

## **Appendix D**

### **Consent Form Templates: NGO leaders and individuals (first two) with impairments (second two)**

#### **VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY**

#### **Informed Consent for Participants**

#### **in Research Projects Involving Human Subjects**

Title of Project: Social Justice for the People with Disabilities in Brazil: Legal, Political and Moral Discourses

Investigator(s) Lyusyena Kirakosyan, Doctoral Candidate; Max Stephenson Jr., Faculty Advisor

#### **Purpose of this Interview**

We ask for your participation in an interview. The purpose of the interview is to gain insight into the foundational concepts of justice on which your disability advocacy NGO – Non-Governmental Organization - predicated its claims.

We hope to identify some of the different views of justice reflected in your organizational mission and values, as well as how do you frame the population with disabilities in your discourses.

Overall, we will interview about five national NGOs which have been active in the process of elaboration and negotiation of the UN Convention representing Brazilian civil society with the United Nations in New York and its active promotion with Brazilian legislators. Your interview will last about 60 minutes.

#### **Procedures**

We ask for your participation in an interview conducted by Lyusyena Kirakosyan. Ms. Kirakosyan is a doctoral student in the Alliance for Social, Political, Ethical and Cultural Thought program at Virginia Tech. She will use your interview responses in completing her doctoral dissertation. Her conversation with each person who agrees to be interviewed will be audio recorded (or video recorded in case of the use of sign language). You have an option to decline audio/video recording, in which case your proposed interview will not take place. Assuming you agree to a recorded interview, Ms. Kirakosyan will produce a transcript of the audio or video (when applicable) recording of your interview following its completion. That transcription will be mailed to you to provide you an opportunity to check and comment on its factual accuracy, as you might wish. Interview transcripts will be used only for fact checking and for quotations in Ms. Kirakosyan's dissertation and related research efforts. Interview files and transcriptions, as well as all interviewee identifying information will be electronically stored on Ms. Kirakosyan's password-protected computer and backed up on an external data storage device (flash-drive). While in Brazil, the external data storage device will be stored in a locked filing cabinet at her residence. On her return to the United States that device will be stored in a locked filing cabinet in her university office at Virginia Tech. All data with participant identifying information will be destroyed three years following successful defense of Ms. Kirakosyan's dissertation. Meanwhile, all data without identifying information will be securely kept on Ms. Kirakosyan's computer. Only she and her Academic Advisor,

Dr. Max Stephenson, will have access to the recordings. Ms. Kirakosyan will make every effort not to reveal your individual identity or link specific observations to you in her findings.

Your participation is voluntary. Participation will involve a single interview. If you have any questions about this research, please feel free to contact us. Our contact information is listed below.

**Risks**

We believe the risk of harm to you from your participation in this study is very low. In any case, risks from this study are no greater than those you might face in your daily life.

**Benefits**

We do not guarantee a personal benefit to you from your participation. Though, we are grateful for your consideration. We also hope that this may be a good opportunity to reflect on your experiences. If you are interested in the results of this research, please check one of the two choices below. Please also provide your mailing address if you would like to receive a copy of the final paper, after it is translated to Portuguese.

Please check:

\_\_\_\_\_

**YES**, I would like to receive a copy of the final paper. You may send it to me at the following address:

\_\_\_\_\_

**OR**

\_\_\_\_\_

\_\_\_\_\_

**NO**, I would not like to receive a copy of the final paper.

**Confidentiality and Anonymity**

We ask your *written consent* to allow Ms. Kirakosyan to use your remarks in producing a dissertation and research articles/book from this research. This may include papers or publications. We are the only ones who will have access to recordings and transcripts related to this project. You may choose to speak “on the record” or “off the record” throughout our conversation. If you choose to speak off the record for all or a portion of your conversation with

Ms. Kirakosyan your request will be honored and the audio/video recorder switched off. Your responses “off the record” will not be attributed to you, even with a pseudonym, but the sense of any comments you offer may inform the study’s findings and be reported without identifying attribution. In any case, we will use pseudonyms to protect your identity and no direct attribution of specific responses will be made to you whether you offer your comments on or off the record. However, we cannot guarantee that using alternate names will completely protect your identity, given the nature of the research.

The Virginia Tech Institutional Review Board (IRB) may see this study’s data. This would occur for auditing purposes only. The IRB is responsible for ensuring that any human subjects involved in research are protected. The Board’s contact information appears below.

**Compensation**

We are unable to provide payment for you to participate.

**Freedom to Withdraw**

You are free to withdraw from this research at any time. You are also free NOT to answer questions.

**Your Responsibilities and Permission**

I, \_\_\_\_\_, agree to participate in this research. I understand it will focus on my knowledge and experiences as a leader of a disability advocacy Non-Governmental Organization in Brazil. I am 18-years-old or older.

I have read and understood this document. I understand the purposes of this research. By signing below, I give my voluntary consent to participate and acknowledge of receiving a copy of this Informed Consent form:

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

**Should I have any questions about this research or its conduct, or questions about my rights, I may contact:**

**Faculty Advisor:**

Dr. Max O. Stephenson, Jr.  
Virginia Tech Professor  
540-231-7340  
[mstephen@vt.edu](mailto:mstephen@vt.edu)

**Investigator:**

Lyusyena Kirakosyan  
Doctoral Candidate  
(11) 3719-1476  
[lyusyena@vt.edu](mailto:lyusyena@vt.edu)

**IMPORTANT:**

**If you have any questions about this study, you may also contact Dr. David Moore, Chair Virginia Tech Institutional Review Board for the Protection of Human Subjects, telephone: (540) 231-4991; email: [moored@vt.edu](mailto:moored@vt.edu); address: Research Compliance Office, 2000 Kraft Drive, Suite 2000, Blacksburg, VA 24061.**

**THANK YOU FOR YOUR TIME AND PARTICIPATION**

# INSTITUTO POLITECNICO E UNIVERSIDADE ESTADUAL DE VIRGINIA

## Consentimento Informado para Participantes em Projeto de Pesquisa Envolvendo Humanos

Título do Projeto: Justiça Social para as Pessoas com Deficiência no Brasil: Discursos Legais, Políticos e Morais

Investigadores: Lyusyena Kirakosyan, Candidata à Doutorado; Max Stephenson Jr., Conselheiro Acadêmico

### Objetivo desta Entrevista

A sua participação é solicitada numa entrevista que terá por objetivo a compreensão de conceitos fundamentais de justiça que formam a base de reivindicações das Organizações Não-Governamentais sobre direitos das pessoas con deficiência.

Espera-se identificar algumas das diferentes visões de justiça refletidas na missão e nos valores das organizações, bem como cada uma delas enquadra a população com deficiência nos seus discursos.

No total, pretendemos entrevistar aproximadamente cinco ONGs que foram ativas no processo de elaboração e negociação da Convenção da ONU, representado a sociedade civil brasileira em Nova Iorque, bem como a promoção da Convenção com os legisladores brasileiros. A sua entrevista terá duração de aproximadamente 60 minutos.

### Procedimentos

É solicitada sua participação em entrevista conduzida pela Lyusyena Kirakosyan, , estudante de Doutorado no Programa de Aliança em Teoria Social, Política, Ética e Cultural na Universidade Virginia Tech. Sta. Kirakosyan utilizará as suas respostas para completar a sua tese de doutorado. A conversa com cada participante será audio gravada ou vídeo gravada (no caso do uso de LIBRAS). O(A) Sr(a) tem opção de recusar a audio/video gravação, cancelando a entrevista. Caso concordar em ter a sua entrevista gravada, a Sta. Kirakosyan transcreverá a audio/video gravação da sua entrevista alguns dias após o acontecimento. As transcrições serão disponibilizadas ao entrevistado para fornecer uma oportunidade de checar a precisão de fatos e comenta-los, caso julgar oportuno. As transcrições serão usadas somente para checar os fatos e para citação na tese e nos trabalhos relacionados da Sta. Kirakosyan. Os arquivos de entrevistas e as transcrições, assim como todas as informações de identificação dos participantes serão guardadas em versão digital no computador da Sta. Kirakosyan protegido por senha. Uma cópia de segurança será guardada num dispositivo de armazenamento externo (pen-drive). No Brasil, este dispositivo será guardado num gaveteiro com trava. Na volta aos Estados Unidos, o dispositivo será guardado num gaveteiro com trava no escritório universitário da Sta. Kirakosyan na Virginia Tech. Todas as informações com identificação dos participantes serão destruídas três anos após a defesa da tese. Porém, as informações que não contém

identificação dos participantes serão seguramente guardadas no computador da Sta. Kirakosyan. Somente Sta. Kirakosyan e o seu Conselheiro Acadêmico, Dr. Max Stephenson, terão acesso às gravações. A Sta. Kirakosyan fará o possível para não revelar a sua identidade ou relacionar as observações específicas nas conclusões com o(a) Sr.(a).

A sua participação é voluntária e envolve somente uma entrevista. Caso tiver dúvidas sobre esta pesquisa, por favor, entre em contato conosco ou com o Diretor do Conselho de Revisão Institucional da Virginia Tech. As nossas informações de contato estão listadas abaixo.

### **Riscos**

Acreditamos que a sua participação nesta pesquisa não lhe causará prejuízo. De qualquer forma, o risco associado com esta pesquisa não é maior dos que acontecem na sua vida diária.

### **Benefícios**

Nós não podemos garantir seu benefício pessoal resultante de participação nesta pesquisa, mas agradecemos pela sua consideração. Esperamos que esta seja uma boa oportunidade de refletir nas suas experiências. Se estiver interessado nos resultados desta pesquisa, por favor, indique a sua escolha abaixo, provendo o seu endereço caso quiser receber uma cópia deste trabalho, quando ele foi traduzido para o português.

Por favor indique:

\_\_\_\_\_

**SIM**, Eu gostaria de receber uma cópia do trabalho final. Por favor encaminhe o pelo seguinte endereço:

\_\_\_\_\_

**OU**

\_\_\_\_\_

\_\_\_\_\_

**NÃO**, Eu não gostaria de receber uma cópia do trabalho final.

### **Confidencialidade e Anonimidade**

Nós pedimos o seu **consentimento por escrito** para permitir a utilização dos seus comentários nos trabalhos e possíveis publicações que resultem desta pesquisa. Nós seremos os únicos que terão acesso às gravações e transcrições. O(A) Sr.(a) pode escolher falar “para o registro” ou “confidencial” durante a nossa conversa. Nos momentos que escolher a falar confidencialmente, nós honraremos seu pedido de confidencialidade e o gravador será desligado. As suas respostas confidenciais não serão atribuídas ao (à) Sr(a), mesmo com um pseudônimo, mas o sentido geral do seus comentários poderão informar as conclusões desta pesquisa e serem inclusos sem a sua identificação. De qualquer maneira, nós usaremos um pseudônimo para proteger a sua identidade e não atribuiremos respostas específicas ao (à) Sr(a) independente se “para o registro” ou “confidencial”. Porém, não podemos garantir que o uso de um nome-fantasia protegerá a sua identidade completamente, dada a natureza da pesquisa.

O Conselho de Revisão Institucional de Virginia Tech pode requerer os dados desta pesquisa com o objetivo de auditoria. O Conselho é responsável por assegurar que todo indivíduo envolvido na pesquisa esteja protegido. As informações de contato do Conselho estão listadas abaixo.

### **Compensação**

Não podemos oferecer-lhe pagamento para a Vossa participação.

### **Liberdade de Retirar-se**

O (A) Sr.(a) tem liberdade de retirar-se desta pesquisa a qualquer momento e/ou escolher a não responder às perguntas.

### **Responsibilidades e Consentimento**

Eu, \_\_\_\_\_, concordo em participar desta pesquisa. Eu entendo que a pesquisa será baseada no meu entendimento, conhecimento e nas minhas experiências no papel de liderança de uma Organização Não-Governamental que atua na defesa de direitos das pessoas com deficiência em Brasil. Possuo idade acima de 18 anos.

Eu li e entendi este documento. Eu compreendo os objetivos desta pesquisa. Assinando abaixo, estou dando a minha permissão em participar e reconheço o recebimento de uma cópia deste Formulário de Consentimento:

\_\_\_\_\_  
Assinatura

\_\_\_\_\_  
Data

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Assinatura

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Data

**Caso tiver dúvidas sobre esta pesquisa ou a sua conduta ou dúvidas sobre os meus direitos, eu posso entrar em contato com:**

**Investigador Primário/Conselheiro Acadêmico:** **Investigadora Adjunta:**

Dr. Max O. Stephenson, Jr.

Professor de Virginia Tech

540-231-7340

[mstephen@vt.edu](mailto:mstephen@vt.edu)

Lyusyena Kirakosyan

Candidata à Doutorado

(11) 3719-1476

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

**IMPORTANTE:**

**Caso tiver dúvidas sobre esta pesquisa, o (a) Sr.(a) também poderá entrar em contato com o Dr. David Moore, Diretor do Conselho de Revisão Institucional para Proteção de Sujeitos Humanos de Virginia Tech, telefone: 1 540 231 4991; email: [moored@vt.edu](mailto:moored@vt.edu); endereço: Escritório de Compliance, 1880 Pratt Drive, Suite 2006 (0497), Blacksburg, VA 24061.**

**AGRADECEMOS PELO SEU TEMPO E PARTICIPAÇÃO**

**VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY**

**Informed Consent for Participants  
in Research Project Involving Human Subjects**

Title of Project: Social Justice for People with Disabilities in Brazil: Legal, Political and Moral Discourses

Investigator(s) Lyusyena Kirakosyan, PhD. Candidate; Max Stephenson Jr., Faculty Advisor

**Purpose of this Interview:**

We ask for your participation in an interview. In the interview, we will focus on your (or your family member's) understandings and experiences as a person with disabilities.

We hope to identify some of the different ideas and experiences of people with disabilities like yourself (or your family member), regarding justice in your daily lives, and what needs to be changed in Brazilian society, in your view, to make it more just.

Overall, we will interview approximately ten people with disabilities in the city of São Paulo who agree to participate in this study. Your interview will last about 60 minutes.

**Procedures**

We ask for your participation in an interview conducted by Lyusyena Kirakosyan. Ms. Kirakosyan is a doctoral student in the Alliance for Social, Political, Ethical and Cultural Thought program at Virginia Tech. She will use your interview responses in completing her doctoral dissertation. Her conversation with each person who agrees to be interviewed will be audio recorded (or video recorded in case of the use of sign language). You have an option to decline audio/video recording, in which case your proposed interview will not take place. Assuming you agree to a recorded interview, Ms. Kirakosyan will produce a transcript of the audio or video (when applicable) recording of your interview following its completion. That transcription will be mailed to you to provide you an opportunity to check and comment on its factual accuracy, as you might wish. Interview transcripts will be used only for fact checking and for quotations in Ms. Kirakosyan's dissertation and related research efforts. Interview files and transcriptions, as well as all interviewee identifying information will be electronically stored on Ms. Kirakosyan's password-protected computer and backed up on an external data storage device (flash-drive). While in Brazil, the external data storage device will be stored in a locked filing cabinet at her residence. On her return to the United States that device will be stored in a locked filing cabinet in her university office at Virginia Tech. All data with participant identifying information will be destroyed three years following

successful defense of Ms. Kirakosyan’s dissertation. Meanwhile, all data without identifying information will be securely kept on Ms. Kirakosyan's computer. Only she and her Academic Advisor, Dr. Max Stephenson, will have access to the recordings. Ms. Kirakosyan will make every effort not to reveal your individual identity or link specific observations to you in her findings.

Your participation is voluntary. Participation will involve a single interview. If you have any questions about this research, please feel free to contact us or the Chair of the Institutional Review Board at Virginia Tech. Our contact information is listed below.

**Risks**

We believe the risk of harm to you from your participation in this study is very low. In any case, risks associated with this study are no greater than those you might face in your daily life.

**Benefits**

We cannot guarantee a personal benefit to you from your participation in this research, but we are grateful for your consideration. We also hope that this may be a good opportunity to reflect on your experiences. If you are interested in the results of this research, please check one of the two choices below. Please also provide your mailing address if you would like to receive a copy of the final paper, after it is translated to Portuguese.

Please check:

\_\_\_\_\_ **YES**, I would like to receive a copy of the final paper. You may send it to me at the following address:

\_\_\_\_\_  
\_\_\_\_\_

**OR**

\_\_\_\_\_ **NO**, I would not like to receive a copy of the final paper.

**Confidentiality and Anonymity**

We ask your *written consent* to allow Ms. Kirakosyan to use your remarks in producing a dissertation and research articles/book from this research. This may include papers or publications. We are the only ones who will have access to recordings and transcripts related to this project. You may choose to speak “on the record” or “off the record” throughout our conversation. If you choose to speak off the record for all or a portion of your conversation with

Ms. Kirakosyan your request will be honored and the audio/video recorder switched off. Your responses “off the record” will not be attributed to you, even with a pseudonym, but the sense of any comments you offer may inform the study’s findings and be reported without identifying attribution. In any case, we will use pseudonyms to protect your identity and no direct attribution of specific responses will be made to you whether you offer your comments on or off the record. However, we cannot guarantee that using alternate names will completely protect your identity, given the nature of the research.

The Virginia Tech Institutional Review Board (IRB) may see this study’s data. This would occur for auditing purposes only. The IRB is responsible for ensuring that any human subjects involved in research are protected. The Board’s contact information appears below.

**Compensation**

We are unable to provide payment for you to participate.

**Freedom to Withdraw**

You are free to withdraw from this research at any time. You are also free NOT to answer questions, as you elect.

**Your Responsibilities and Permission**

I, \_\_\_\_\_, agree to participate in this research. I understand it will focus on my understandings and experiences as a citizen with disabilities in São Paulo, Brazil. I am 18-years-old or older.

I have read and understood this document. I understand the purposes of this research. By signing below, I give my voluntary consent to participate and acknowledge receiving a copy of this Informed Consent form:

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

**Should I have any questions about this research or its conduct, or questions about my rights concerning it, I may contact:**

**Primary Investigator/Faculty Advisor:**

Dr. Max O. Stephenson, Jr.

Virginia Tech Professor

540-231-7340

[mstephen@vt.edu](mailto:mstephen@vt.edu)

**Co-Investigator:**

Lyusyena Kirakosyan

Doctoral Candidate

(11) 3719-1476

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

**IMPORTANT:**

**If you have any questions about this study, you may also contact Dr. David Moore, Chair Virginia Tech Institutional Review Board for the Protection of Human Subjects, telephone: (540) 231-4991; email: [moored@vt.edu](mailto:moored@vt.edu); address: Research Compliance Office, 2000 Kraft Drive, Suite 2000, Blacksburg, VA 24061.**

**THANK YOU FOR YOUR TIME AND PARTICIPATION**

## **INSTITUTO POLITECNICO E UNIVERSIDADE ESTADUAL DE VIRGINIA**

### **Consentimento Informado para Participantes**

#### **em Projeto de Pesquisa Envolvendo Humanos**

Título do Projeto: Justiça Social para as Pessoas com Deficiência no Brasil: Discursos Legais, Políticos e Morais

Investigadores: Lyusyena Kirakosyan, Candidata à Doutorado; Max Stephenson Jr., Conselheiro Acadêmico

#### **Objetivo desta Entrevista**

Nós pedimos a sua participação numa entrevista que se focará em entendimentos sobre e experiências com a deficiência seus ou do membro de sua família.

Esperamos identificar algumas das diferentes visões e experiências de justiça de pessoas com deficiência refletidas na sua vida diária, e o que precisa ser mudado na sociedade brasileira para torná-la mais justa, ao seu ponto de vista.

No total, pretendemos a entrevistar aproximadamente dez pessoas com deficiência que gostarem de participar nesta pesquisa na cidade de São Paulo. A sua entrevista terá duração de aproximadamente 60 minutos.

#### **Procedimentos**

Nós pedimos a sua participação numa entrevista conduzida pela Lyusyena Kirakosyan. Sta. Kirakosyan é estudante de Doutorado no Programa de Aliança em Teoria Social, Política, Ética e Cultural na Universidade Virginia Tech. Sta. Kirakosyan utilizará as suas respostas na entrevista para completar a sua tese de doutorado. A conversa com cada participante será audio gravada (video gravada no caso de uso de LIBRAS). O(A) Sr(a) tem opção de recusar a audio/video gravação, cancelando a entrevista. Supondo que o(a) Sr.(a) concordar a ter a sua entrevista gravada, a Sta. Kirakosyan transcreverá a audio/video gravação da sua entrevista alguns dias após o acontecimento. As transcrições serão disponibilizadas ao (à) Sr.(a) para fornecer uma oportunidade de checar a precisão de fatos e comentar caso quiser. As transcrições serão usadas somente para checar os fatos e para citação na tese e nos trabalhos relacionados da Sta. Kirakosyan. Os arquivos de entrevistas e as transcrições, assim como todas as informações de identificação dos participantes serão guardadas em versão digital no computador da Sta. Kirakosyan protegido pela senha. Uma cópia de segurança será guardada num dispositivo de armazenamento externo (pen-drive). No Brasil, este dispositivo será guardado num gaveteiro com trava. Na volta aos Estados Unidos, o dispositivo será guardado num gaveteiro com trava no escritório universitário da Sta. Kirakosyan na Virginia Tech. Todas as informações com identificação dos participantes serão destruídas três anos após a defesa da tese. Porém, as informações que não contém identificação dos participantes serão seguramente guardadas no computador da Sta. Kirakosyan. Somente Sta. Kirakosyan e o seu Conselheiro Acadêmico, Dr. Max Stephenson, terão acesso às gravações. A Sta. Kirakosyan fará o possível para não revelar a sua identidade ou relacionar as observações específicas nas conclusões com o(a) Sr.(a).

A sua participação é voluntária e envolve somente uma entrevista. Caso tiver dúvidas sobre esta pesquisa por favor entre em contato conosco ou com o Diretor do Conselho de Revisão Institucional da Virginia Tech. As nossas informações de contato estão listadas abaixo.

### **Riscos**

Acreditamos que a sua participação nesta pesquisa não causará prejuízo. De qualquer forma, o risco associado com esta pesquisa não é maior dos que acontecem na sua vida diária.

### **Benefícios**

Nós não podemos garantir seu benefício pessoal resultante de participação nesta pesquisa, mas agradecemos pela sua consideração. Esperamos que esta seja uma boa oportunidade de refletir sobre as suas experiências. Se estiver interessado nos resultados desta pesquisa, por favor indique a sua escolha abaixo, provendo o seu endereço caso quiser receber uma cópia deste trabalho, quando ele foi traduzido para o português.

Por favor indique:

\_\_\_\_\_ **SIM**, Eu gostaria de receber uma cópia do trabalho final. Por favor encaminhe o pelo seguinte endereço:

\_\_\_\_\_  
\_\_\_\_\_

**OU**

\_\_\_\_\_ **NÃO**, Eu não gostaria de receber uma cópia do trabalho final.

### **Confidencialidade e Anonimidade**

Nós pedimos o seu *consentimento por escrito* para permitir a Sta. Kirakosyan a usar os seus comentários nos trabalhos e possíveis publicações que resultem desta pesquisa. Nós seremos os únicos quem ter terão acesso às gravações e transcrições. O(A) Sr.(a) pode escolher a falar “para o registro” ou “confidencial” durante a nossa conversa. Nos momentos que escolher a falar confidencialmente, nós honramos seus pedidos específicos de confidencialidade e o gravador será desligado. As suas respostas confidenciais não serão atribuídas ao (à) Sr(a), mesmo com um pseudônimo, mas o sentido geral do seus comentários poderão informar as conclusões desta pesquisa e serem inclusos sem a sua identificação. De qualquer maneira, nós usaremos um

pseudônimo para proteger a sua identidade e não atribuiremos respostas específicas ao (à) Sr(a) independente das respostas sejam “para o registro” ou “confidencial”. Porém, não podemos garantir que o uso de um nome-fantasia protegerá a sua identidade completamente, dada a natureza da pesquisa.

O Conselho de Revisão Institucional de Virginia Tech pode requerer os dados desta pesquisa com o objetivo de auditoria. O Conselho é responsável por assegurar que todo indivíduo envolvido na pesquisa esteja protegido. As informações de contato do Conselho estão listadas abaixo.

### **Compensação**

Não podemos oferecer-lhe pagamento para a Vossa participação.

### **Liberdade de Retirar-se**

O (A) Sr.(a) tem liberdade de retirar-se desta pesquisa a qualquer momento e/ou escolher a não responder às perguntas.

### **Responsabilidades e Consentimento**

Eu, \_\_\_\_\_, concordo participar nesta pesquisa. Eu entendo que a pesquisa será baseada no meu entendimento e nas minhas experiências como um cidadão com deficiência em São Paulo, Brasil. Possuo idade acima de 18 anos.

Eu li e entendi este documento. Eu compreendo os objetivos desta pesquisa. Assinando abaixo, estou dando a minha permissão em participar e reconheço o recebimento de uma cópia deste Formulário de Consentimento:

\_\_\_\_\_  
Assinatura

\_\_\_\_\_  
Data

**Caso tiver dúvidas sobre esta pesquisa ou a sua conduta ou dúvidas sobre os meus direitos, eu posso entrar em contato com:**

<b>Investigador Primário/Conselheiro Acadêmico:</b> Dr. Max O. Stephenson, Jr. Professor de Virginia Tech 540-231-7340	<b>Investigadora Adjunta:</b> Lyusyena Kirakosyan Candidata à Doutorado (11) 3719-1476
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[mstephen@vt.edu](mailto:mstephen@vt.edu)

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

**IMPORTANTE:**

**Caso tiver dúvidas sobre esta pesquisa, o (a) Sr.(a) também poderá entrar em contato com o Dr. David Moore, Diretor do Conselho de Revisão Institucional para Proteção de Sujeitos Humanos de Virginia Tech, telefone: 1 540 231 4991; email: moored@vt.edu; endereço: Escritório de Compliance, 2000 Kraft Drive, Suite 2000, Blacksburg, VA 24061.**

**AGRADECEMOS PELO SEU TEMPO E PARTICIPAÇÃO**