Citizenship, Rights and Persons with Disabilities in India

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Introduction

The concept of citizenship revolves around questions of rights, participation and governance. According to Tilly (2004), citizenship consists of mutual rights and obligations binding governmental agents to people subjected to the government’s authority and is envisaged as a vital part of the nation-state. Citizenship offers a framework to describe the relationship between citizens and the state in terms of mutual rights and responsibilities, that is, within democracies. This relationship is reflected in the four components of citizenship—status, rights, identity (e.g. in a nation state) and participation (Delanty 2000). The United Nations Universal Declaration of Human Rights 1948 highlights the responsibility of a welfare state to ensure basic rights for all its citizens, shifting the focus to the individual located within a neo-liberal framework where rights-based legislations guarantee basic entitlements that empower citizens to place claims on the state and demand accountability for implementation. Despite such national and international developments, persons with disabilities are marginalized within Indian society in various ways, affected by the stigma established by the religious and medical discourses; this is why the framing of a legal instrument that can offer not just redress but a positive structuring of the issue of disability became imperative. This paper proposes to examine the ways in which the rights of persons with disabilities were understood and interpreted during the process of drafting a new law for disabled people in India, guided by the United Nations Convention on Rights of Persons with Disabilities (UNCRPD). The paper explores the processes whereby disability activists across impairment categories, themselves a product of the very social context that looks at disabled people negatively, envisage an inclusive world that would respect the rights and dignity of people with impairments.
The modern welfare state seemingly encourages democratic participation by placing a premium on autonomy and individuality, yet promotes welfare as a benevolent gesture, where responsibility is taken for people who, due to inequality of opportunity, are excluded and marginalized from political, economic and social structures. The discourse around social rights in a modern society defined by social inequalities recognizes the need for social welfare policies so that all members of the national community are able to live the “life of a civilized being according to the standards prevailing in the society” (Marshall 1950:11), fulfil their responsibilities as full citizens, and participate in governance, society and economy. In India citizenship was interpreted on a philosophical and ideological basis, and envisaged the inclusion of all people born in its geographical territory, which vision has, however, gradually shifted to defining citizenship by parentage (Roy 2020); this provides the state with opportunities for neglecting other rights, namely, substantive equality and justice. As the cultural concept of nation became accepted as the basis of sovereignty and political identity of citizenship, it also resulted in the acculturalization of the idea of citizenship. The Indian Constitution recognizes differentiated citizenship so that members of specific ethnic, linguistic, racial and religious groups and universalist frameworks of citizenship efface the manner in which citizenship is differentially experienced along axes of class, caste, gender and language. Roy (2020) elaborates, saying that formal/legal equality does not easily translate itself into substantive equality unless all citizens are practically able to exercise their rights and legal capacities conferred by citizenship. The plain truth is that, in India, minorities are unable to exercise such rights or legal capacities because of the institutional bias against them, which ignores the specific needs of people belonging to disadvantaged groups that are affected by the generalized application of uniform frameworks/standards of citizenship.

Social participation and enjoyment of citizenship by persons with disabilities is usually limited by able bodied socio-cultural values and ideologies, and structural and infrastructural barriers that create marginality through discriminatory and disempowering practices (Thomas 2004). As citizenship is linked to fulfilment of social responsibility, states focus on normalization of persons with disabilities through medical interventions, therapy, special education and social security provisions (Oliver 1990; Symonds and Kelly 1998), rather than changing the disabling social, political and physical contours of society (Drake 1994). Stone (1984) posited that, specific definitions of disability in welfare states juxtapose need-based and work-based systems of distributive justice, wherein marginalized groups are entitled to privileges in the form of social aid. Welfare provisions lead to the individualization of disability and ignore the collective disabling experiences that impede participation in society, breeding power hierarchies that deny personhood and citizenship to the person with a disability (Oliver 1990). As the social model globally highlighted the oppression of being treated as second class citizens irrespective of the cultural or political context (Campbell and Oliver 1996), it focused on contesting and transforming the power structures disabled people find themselves mired in. According to Tarrow (1994), social movements such as the disability movement, unite people with lack of regular access to institutions and those seeking to establish new or contested claims, and prove effective when they build or illuminate solidarities that have shared meaning within particular groups, situations and political cultures. However, as Horn (2013) points out, social movements rely on dense and familiar social relations and cultural symbols for enduring against different odds. The global disability movement attempted to build
solidarities on the broad idea of oppression among people from different categories of impairment. Yet Morris (2001) highlighted that some people’s experience of their bodies (their impairments) places them at much greater risk of losing their human (and civil) rights. There have been debates between disability scholars and activists pointing to the fractured unity between groups of people with different impairments, with capacity and selfhood being allowed or denied based on perceptions of ability, while some have attempted to posit independence as self-sufficiency or the capability of individuals with disabilities in terms of choice and control (Kroger 2009).

In the Global South, however, the political rhetoric of the social model is pitched against the basic survival needs of persons with disabilities (Grech 2009), where participation is hindered by lack of resources and aspersions on capacity. In a vast yet poor country such as India, where cultural ideologies and communitarian mechanisms hold sway, the individualized framing of rights based on notions of capacity and ability, and hence access to citizenship, critically affect the everyday lives of persons with disabilities. In India, a rights-based welfare approach was advocated by civil society mobilizations between 1980–2000 not only to make the state more accountable, but to gain access to, or share in its power (Mehta 2009). However, the executive state tended to respond to civil society pressures only when the activist courts instructed them to act (Chandoke 2007). Such proactive court judgements further stimulated the move towards rights-based legislations with procedural requirements to ensure greater transparency and create spaces for citizen involvement. This, buttressed by India’s new welfare regime reinforced by landmark laws, has introduced a language of citizenship that recognizes a right to basic socio-economic entitlements.

The legal frameworks recognizing persons with disabilities as citizens of India appeared in the context of civil society activism and judicial interventions. In this deeply inequitable country, lobbying by different disability groups led, till 1995, to sporadic state responses in the form of piecemeal programs and welfare entitlements for persons with disabilities, shaped primarily by the ideologies and demands of service providers and bureaucrats, which did little to enable effectual citizenship for persons with disabilities. Since 1990s, disability activists have used the social model to advocate for disability rights, but have had to settle for rehabilitation programs and specific entitlements, with little commitment towards the changing of attitudes and social and physical arrangements, or promoting inclusion in diverse ways. However, since 2000s, disability groups influenced by the UNCRPD, to which India is a signatory, have pushed for proactive laws, in order to claim citizenship rights and access a better quality of life.

Yet, the idea of disability as a socially constructed complex of power relationships has not been fully comprehended or realized within the disability movement in India. The movement is largely spearheaded by the disability “sector” in India, a motley group of persons with disabilities themselves and organizations working for and with disabled people, dominated by rehabilitation professionals and service providing agencies, including state funded National Institutes for medical rehabilitation and therapy, civil society agencies such as special schools, rehabilitation centers and NGOs. These medical and rehabilitation professionals/therapists and special schools have influenced to a great extent, the ways in which programs have been rolled out for different impairment categories across the country, sucking in the disabled persons’ and parents’ collectives into the medicalized discourse. The power of the collective and concentrated expert voices located in state run, sponsored and regulated specialized
centers was in contrast to the disabled population dispersed across the country, with little economic clout, voice or lobbying power in political terms. While, since the 2000s, national and state level activists and networks of Disabled People's Organisations (DPOs) have challenged the dominance of the state promoted medical/rehabilitation fraternity, they have remained subservient to the larger medicalized discourse of disability to access state welfare. Thus the disability sector comprises actors determined by varied positionalities and foci—medical doctors treating different impairment categories, rehabilitation professionals such as physiotherapists, prosthetists and orthotists, and other therapists who highlight appropriate rehabilitation therapies, special educators who focus on individualized education plans, organizations providing a range of services for disabled people and their families, juxtaposed with urban disability activists and self-advocates discussing rights-based frameworks with large networks of DPOs spread across the country. The tensions between knowledge of professionals and experiential knowledge, between professionals and urban based disability activists, are limited to specific disabilities, despite claims of being inclusive of disabilities. In such a power struggle, the citizenship concerns of groups rendered invisible among persons with disabilities, which include those with sensory impairments, mental health issues, intellectual, developmental and learning disabilities, are largely absent. These hierarchies reflect power differentials, not only within the sector but also in the socio-cultural attitudes towards people with different kinds of disabilities that is bred within society itself, intersecting with gender, caste and religious identities as well. This is in tandem with Galvin’s (2003) question to people with disabilities, “how can we claim unity without falling into the same exclusionary practices that have served to create our divisive identifications in the first place?” (p. 675).

The issues around power and voice become even more complicated when the insider/outsider binaries are mobilized during processes of negotiations and collaborations between different groups: persons with disabilities, parents and families, medical and rehabilitation professionals, special educators, therapists, service providers etc. Gest and Gray (2018) argue that the silencing of citizens is a result of structural inequality between and among groups, unequal distributions of wealth and power that seek to disempower particular categories. When silent disempowered groups seek greater control over what is said and done in their name, debates around citizenship become more diverse and meaningful. In the light of the trajectory of events that led to the drafting and subsequent passage of the Rights of Persons with Disabilities Act (RPDA) 2016, this paper attempts to explore the ways in which the debates and discussions around the process of drafting legal provisions envisaged citizenship for diverse groups of disabled people. As citizenship binds government agents to categories of people subjected to the state’s authority, the paper illustrates ways in which actors within the disability rights movements interacted among themselves and with the state to make claims for citizenship for different groups of people from different impairment categories, and the ways in which particular power hierarchies attempted to influence claims to rights and entitlements. The paper examines the ways in which the concept of disability, legal capacity and citizenship was debated and constructed in the light of the events and discussions that led to the drafting of the RPD Act in 2016 and uses discourse analysis to understand how citizenship for persons with disabilities was interpreted and understood among the different groups and enshrined as clauses.
within the new law, along with consequent privileges and responsibilities. The next section discusses the relevance of discourse analysis in furthering this understanding.

**Methodological premises**

This paper uses discourse analysis to examine the process of the shaping of disability law in India through discussions and debates that have taken place within a particular socio-historical and political context. Discourse analysis facilitates a deeper understanding of social reality through the exploration of meanings produced by language use and communication, the contexts and processes of these meanings and the practices caused by these meanings. From a sociological standpoint, discourse is defined as any social practice by which individuals imbue reality with meaning (Ruiz 2009) that is socially produced and shared. Schutz (1962) held that discourse embodies this intersubjectivity in a socially organized world and can be explained through analysis. Discourse analysis as a social research method therefore entails the process of examining the interrelationship between social intersubjectivity and the social order, between social practice and structure, and the ways in which these influences and co-create one another. Discourse analysis relies on interpretation of language and practices within particular social contexts to explain the discourse as information, ideology or a social product. In the attempt to locate the discourse on disabled citizenship, as understood by disability activists and invested actors, the author will be drawing on the debates and discussions that took place during the framing of the new rights-based law for persons with disabilities in India, the Rights of Persons with Disabilities Act (RPDA) 2016. The author herself was a party to the discussions and the process itself, which involved major players within the disability sector in India from 2011 to 2013.

As already mentioned, the disability sector in India comprises diverse groups of people, all invested in the welfare and rights of persons with disabilities. The disability sector includes disability rights activists, who are mostly disabled people, along with members of organizations that work with disabled people in different parts of the country, and an entire range of rehabilitation professionals from specialists in locomotor disabilities, to technicians for hearing impairments, to special educators and counsellors for intellectual and psycho-social disabilities as well as administrators at different levels of government who regulate the range of services for persons with disabilities in India. This disability sector reflects the shifting power dynamics, wherein the disability activists and the movement in India is contesting with the voices of the state and administrators and programs for welfare, claiming space for themselves within the disability discourse. While the discourse is still largely dominated by western ideas of individual autonomy and independence, there is increasing awareness of local and community-based solutions that work differently for different groups of disabled people. Yet this disability consciousness is predominant primarily among educated middle and upper middle-class persons with disabilities living in urban contexts, with some of the DPOs in the rural South demonstrating strong identity construction and community mobilizations. Largely, rural disabled people remain under-represented within this disability sector, which is indicative of another dimension of the power hierarchy within the disability sector itself. These internal hierarchies further intersect with social hierarchies existing within the complex social fabric of India, where gender,
Caste class and religion create inequities among the larger populace. There are studies documenting the different ways in which gender and caste cause further marginalization of persons with disabilities (refer to Ghosh 2016a; Mehrotra 2013; Addlakha 2013; Pal 2010). The power tussle witnessed within the disability sector is primarily between the “knowledgeable” professionals, who claim hegemony over the solutions they offer to normalize disabled people, and “experiential” voices that represent varied lives, based not only on impairment but on other identity markers too. Further, as will be explored later in this paper, there has emerged a hierarchy within disability categories themselves, wherein people with blindness and locomotor disability have assumed leadership positions within the disability movement, silencing and ignoring the concerns of voiceless and invisible groups. Many of these urban disability leaders reflect the socio-cultural values of dependence and paternalism towards the silenced groups, some of whom are attempting to resist and to contest their hegemony in core issues that concern their everyday lives. While the disability sector is widely populated by both men and women (in their rehabilitation, teaching and caring roles), the concerns have been mostly masculinist, highlighting the objective needs of health, education and livelihood, usually considered to be imperatives for disabled people seeking equalization with others. The issues of family, community and legal capacity have, in previous debates, been relegated to peripheral spaces, as the primarily male disability activists with visual, hearing and locomotor impairments have presumed these capacities as equally accessible to all disabled people. With the UNCRPD flagging these specific concerns, the space of the disability sector has become highly contested.

The process of drafting a new disability law in India was a long and rigorous one. India’s ratifying of the UNCRPD in 2007 meant that the existing laws for persons with disabilities had to be modified according to the mandate of the international law to make them more rights-based, which had been demanded a prior by the disability activists. At this historic moment, disability activists chose to press for completely new legislations in consonance with the UNCRPD, leading to the constitution of a Law Drafting Committee in April 2010. This Committee was a variegated one, with different sections of the disability sector represented along with the representatives of different levels of state administration, working in collaboration with a Legal Consultant. There were self-advocates and disability experts representing the different impairment categories inducted in the Committee to ensure that the issues and concerns of all disability groups were included in the legal provisions. The Committee, in the true spirit of the mandate given to it, convened sub-committees to deliberate on the different aspects and issues, in consultation with different groups of persons with disabilities. The Committee also organized 28 state level consultations along with a National Consultation with rights-based organizations and civil society across the country. This final draft bill was put together by the Committee through a process of dialogue and deliberation with the disability sector, through group discussions with disability rights activists and members of civil society, widespread state level consultations across the country and deliberations with legal consultants.

The author was party to this entire process of drafting of the new disability law, as part of a large email discussion group, where minutes of the consultations of different sub committees, reports and updates were posted. Every sub-committee was entrusted with drafting different sections of the law, which were enriched by feedback from activists and professionals from across the country, and then debated within the Committee.
again. This iterative process of drafting the law, reflecting the opinions of diverse
groups and debating clauses, was in a way quite inclusive in the initial stages. Despite
this, the process was dominated in various ways by different groups of people within
the disability sector, primarily urban educated upper middle-class disability activists,
organizations providing a range of services to disabled people with their own concerns
and government representatives keeping in mind the ways in which implementation
would proceed. While there were many women participating in the discourses,
discussions and debates, it is pertinent to point out here that they did not necessarily
reflect the issues and concerns of women, nor was there any challenge to ingrained
patriarchal foregrounding of issues such as health, education and livelihood, and the
right to family, sexual and reproductive health rights. The ideologies, the points of
view and power groups were specifically different; this emerged from the debates in
which the author participated, and in the documents generated by the sub committees
as well as in the correspondence between the stakeholders involved in the entire
process of the drafting of the new law. The email and verbal exchanges at various
points of the process of drafting of the new law, the language used and the arguments
offered clearly reveal the ways in which different groups interpreted rights, and
welfare as well as pressing issues and the needs of and for persons with disabilities in
India. These discussions were often reflective of the dominant socio-cultural ideologies
on ability/disability which shape the politics within the disability sector and towards
persons with disabilities in India. Approaching these debates and discussions in the
course of framing a progressive law as illustration of the ability/disability discourse,
this paper seeks to reveal the intra-disability group politics which are a reflection of
larger societal politics.

The author, being a disability activist herself, was party to many of these email
discussions and consultations across the country, documented through minutes of
meetings and reports that the author had personal access to via email. The author’s
positionality, as an academic and a disability activist, along with her own hesitation to
owning up to a disability identity because she was able to “pass” as “normal,” yet with
her lived experiences of discrimination and negation, all contributed to her particular
disability consciousness and awareness. The author, at that point of time, an engaged
and involved participant in the debates, found herself torn between the different
perspectives of stakeholders from different locations, understanding the concerns of
parents/caregivers, believing in the right to choice and to decision making, while
examining the present socio-cultural context in terms of full legal capacity across
impairment categories. However, I was also, at some level, observing the process of
negotiations, of discussions and debates, of overturning of clauses and insertion of new
ones, of the bitter feuds and strange alliances that developed during the course of the
drafting process. This paper emerges out of the reflections subsequent to the end of the
process of drafting the law, when the author was able to distance herself from the
immediacy of the debates and fierce arguments to consider the ways in which power
dynamics within the disability sector and disability movement actors played a crucial
role in shaping arguments and perspectives, in breaking and creating boundaries, and
affecting the way in which a new disability law was being drafted. The arguments
forwarded here are reflections arising out the primary data, the transcripts of the
e-mails, which represent the varied positions taken by different stakeholders, who are
themselves internally allied or divergent on differing issues. The author has taken care
to ensure that the voices of different groups of stakeholders are adequately presented as data within the analysis, so that differing views on the issues are clearly illustrated.

**Whither Rights? Questions of Difference and Diversity**

The disability sector has been proactive as a pressure group for the adoption of policies for persons with disabilities. The process of drafting the new law in compliance with the UNCRPD, across the country and across categories of disability, initially demonstrated a fallback on the well understood and accepted themes of Entitlements and Authorities for implementing and monitoring the law. Thus, discussions on the provisions of the law focused on specific, objective, measurable provisions and entitlements—disability identity cards, entitlements including housing, bank accounts and provision of reservation in higher education and employment, etc. The rights-based recommendations were generic—barrier free environment, curriculum modification for persons with disabilities and inclusion of disability across courses. The silences around discrimination, stigma and infringement of rights reflect historical socio-cultural assumptions about persons with disabilities as recipients of welfare, and not equal participants in the processes of development. The disability sector, including the DPOs, are influenced by cultural values of disability and dependency, rather than a sense of pride in their identity (Ghosh 2016b), which prevents them from pressing for legal mechanisms for addressing subjective experiences of discrimination. This inability of the disability sector to focus on discrimination can be contrasted with the Prevention of Atrocities against Scheduled Castes and Scheduled Tribes Act 1989, which criminalizes discrimination against these historically discriminated groups in India and provides legal redress. Thus, one wonders, given the historical trajectory of disability as a category and its percolation into the Indian cultural context, what precluded the emergence of a clear and unequivocal rights-based approach?

The answer is partially addressed by examining the disability sector, which is dominated by rehabilitation professionals and service providers, who highlight the positive impact of these interventions in the lives of persons with disabilities, while ignoring the power and politics embedded in the processes of rehabilitation. A leading disability activist Rajan (2011) questioned the composition of the drafting committee, when disagreement arose over provisions of the new law. “If we look at why all these questions have come up about the draft law, there can be only one answer—the drafting committee is full of rehabilitation professionals and parents when it should have been a committee of disabled people, legal experts, parents of persons with specifically intellectual disabilities and rehabilitation professionals” (Rajan 2011). The voices of people in positions of power dominated the discourse and narratives of disability, focusing mostly on socio-economic entitlements couched in the language of rights, and advocating for the normalization of persons with disabilities, which would ensure their own survival, control and dominance. Disabled activists demanded the expulsion of non-disabled people from the process of framing provisions for persons with disabilities, which did not pertain only to rehabilitation professionals but also hinted at nudging out parents and caregivers, thereby favoring a strong disability activist standpoint of “Nothing about Us without Us.” However, these activists and DPOs, who are a vital part of the disability sector, are also enmeshed in a complex network of power relationships, with their own internal hierarchies, pressing for their
individual priorities and reflecting the larger socio-cultural value system within which all are embedded. The following debates will illustrate what D., an activist living with psycho-social disability, felt anguished enough to express, “I have heard about the pecking order within the disability movement but it is coming alive for me in this debate.”\(^1\) While rehabilitation professionals tussled with urban disability activists with particular impairments seeking power over provisions and rights, pitting knowledge against lived experiences framed by cultural ideas about disability, the issues of rural people with disabilities as well as people with sensory impairment were rendered peripheral, and the citizenship concerns of particular groups of persons with disabilities, especially those living with psycho-social disability and intellectual, developmental and learning disabilities were brought forward to be questioned.

Fears around the accommodation of diverse disability groups and their concerns within the same law, along with a lack of clarity about the new law replacing all laws for persons with disabilities in India, stimulated a fierce debate on the demand for one over-arching law to address the concerns of all persons with disabilities or for multiple laws to address the multiple concerns of diverse groups of persons with disabilities. Campaigners of a single law were primarily activists living with cerebral palsy and psycho-social disability, who were frustrated by the National Trust Act 1999 and the Mental Health Act 1987 that allowed contravention of legal capacity for certain groups of persons with disabilities. This group argued that granting full legal capacity in consonance with UNCRPD would make redundant such legislation that often subverted the access to justice for some groups of disabled people. The demand was, therefore, not just for provisions but also for mechanisms of implementation, monitoring and redressal to be built into the framework of the new law to ensure accountability at all levels of society. Arguing for a single comprehensive law, S., a disabled activist in the drafting committee, said, “A group of members in the committee are against the concept of one comprehensive law. Do they realize what they are doing by this? Why don’t they want the implementation, monitoring and redressal mechanism in the same law as the same one that recognizes all rights of all disabled people?” (Rajan 2011).\(^4\) R., another disability activist who resigned from the committee opined, “The concept of comprehensive law is being misunderstood by most committee members. There’s a fear the committee would divide the sector instead of uniting it. I don’t see any possibility of passing five-six different laws at one go.”\(^5\) On the other hand, activists and stakeholders, primarily parents and caregivers of persons with certain impairments, used to the two-law regime (PWD Act 1995 and NT Act 1999) argued that it was almost impossible for one law to guarantee all the rights of all persons with disabilities in the same document. They advocated for a generic law to lay down the substantive provisions, leaving room for flexibility in implementation and monitoring mechanisms depending on context, space and time, to be complemented by laws to address specific issues and concerns of diverse groups of people with impairments. This debate was, however, resolved by the law drafting committee stating clearly that their mandate was to “replace the current disability legislation with a comprehensive law which recognizes all rights of all persons with disabilities,”\(^6\) as delineated in the UNCRPD.
Questions of Legal Capacity: Diverse Voices

One of the most contested provisions in the drafted law was of legal capacity which, in tune with UNCRPD, deems that all persons with disabilities are able to take decisions about their own lives and hence must be recognized as citizens in their own right. Full legal capacity for all persons with disabilities was hotly debated, discussed and contested, not only by the non-disabled professionals, but also by leading disability activists, primarily the blind and the mobility impaired, who argued against full legal capacity for particular groups, specifically people with psycho-social disabilities and persons with intellectual and developmental disabilities. Socio-cultural ideas about people with psycho-social disabilities as well as those with intellectual impairments devalue their abilities and competencies, and determine the way in which dependence/independence is interpreted in India; this leads to the limited development of and/or acceptance of their abilities. Thus, disability activists, located in similar socio-cultural contexts, had imbibed the same ideologies and considered particular groups as incapable of exercising legal capacity. The debates on the legal capacity of these groups in a socio-cultural context where community and state social security mechanisms are weak, had a dual trajectory—on the one hand, people living with psycho-social disabilities protested strongly against the dual standards of capacity and, on the other, parents of persons with intellectual and developmental disabilities wanted support mechanisms to be put in place for their grown children requiring various kinds of support.

In the process of drafting the law, the committee had constituted several subgroups, foremost among which was that on Legal Capacity. During the discussions on the draft law, arguments that strongly advocated for full legal capacity for all persons with disabilities implied that the National Trust Act (NTA) 1999 would stand repealed. The NTA had encoded a model of legal guardianship for specific groups—persons with cerebral palsy, intellectual and developmental disabilities, autism spectrum disorder and multiple disabilities—wherein the extended family was presented as the space for care and protection for them. This law addressed the concerns of middle and upper middle-class families of persons with intellectual impairments, who wanted to ensure proper care for their disabled child after their death and maintenance of their property. Embedded in the law were notions of dependence of persons with severe disabilities and intellectual impairments, in the face of a society and state that had non-existent mechanisms to empower or assist people with intellectual impairments in the exercise of their legal capacity in the absence of parents. People with cerebral palsy had often found guardianship thrust on them under the NTA and hence they wanted to remove such clauses in the new law. During the discussions, R, a person with cerebral palsy said, “The draft says that plenary guardianship is to be abolished. If the basic functions of the National Trust, appointment, monitoring, dismissal and reappointment of guardian, are taken away from the trust, what would be the work of the trust and why should it exist as a separate legislation at all? Or is it that despite abolishing plenary guardianship, the National Trust would continue to do these things?” While parents, guardians, caregivers and special educators pressed for supported decision-making or some form of guardianship, persons with cerebral palsy joined people from the dominant impairment categories in clamoring for full legal capacity.
Being one of the primary concerns, the section on legal capacity was discussed in all the consultations across the country. In one of the consultations in south India, as reported by N., a parent and founder of a self-help group for families and persons with mental and psychiatric disorders, “there were at least three definitions of Legal Capacity; most popular among them is the one which interprets it as Equality before Law! In my view, perhaps the definition is Equality to express one’s will and preferences or equality of personhood.” In another consultation held in north India, J., a parent of an adult with multiple disabilities who has long experience of working with people with intellectual and developmental disabilities concluded, “Persons with disabilities have equal legal rights, but they may not, and should not necessarily be considered as having equal legal capacity under the law. Legal rights do not imply legal capacity. We say that legal capacity is different from ‘competence.’”

Hinting at the hierarchy within the disability categories that prioritized the voices of particular groups, this group comprised primarily of parents of persons with intellectual, developmental and multiple disabilities noted, “The draft seems biased towards physical and sensory disability rather than intellectual disability. Children and people with intellectual impairment (including mental illness, in certain—though NOT all, situations) are often not considered sui juris (having legal capacity under the law). This is a very important protection since, without it, disabled people could sign away their property and the contract be considered binding.” This group in north India therefore re-wrote much of the section on legal capacity to be inserted in the draft law, with provisions aimed at protecting persons with intellectual and developmental disabilities and psycho-social disability. The group recommended that:

“persons with disabilities who do not have the cognitive ability at the relevant time and need support in taking decisions in all matters of life shall have a right to enjoy their legal capacity and be treated equally before the law as persons by being provided with the necessary support in making those decisions affecting their interests through the mechanisms and procedures to be put in place by the NHRC, which shall involve disabled people’s organizations, parents’ associations and other stakeholders in the entire process of evolving the required support measures. Irrespective of their living arrangements, no requests made on behalf of persons with disabilities by the LLC or the natural guardian shall be denied support to exercise legal capacity if so desired.”

This rephrasing of the idea of legal capacity focused primarily on recognition of equality before law for all persons with disabilities co-existing with mechanisms of guided or supported decision-making for certain categories of such persons. This particular consultation, led by an organization that worked primarily with persons with intellectual and developmental disabilities, resonated with the voices of special educators and parents of people with intellectual impairments in expressing concern about their wards’ ability to exercise choice and make decisions. The disability movement’s adoption of the feminist slogan of “Nothing About Us Without Us” had built a clear political agenda which resulted in layers of exclusion and marginalization of parents’ groups in India, muting their voices during the drafting process and representing their protectionist approach as conflicting with the rights-based framework. This move by parents, caregivers and special educators aimed to reclaim the space they had lost to a vociferous disability activism that was dominating the process of drafting the law. In the summary of their discussions, this group from north India recorded, “Participants upheld superiority of Indian Law over and above the UNCRPD in the context of abolition of plenary guardianship. There was no question of
interpreting guardianship as a violation of Rights to Legal Capacity.”

The lobby of parents, caregivers and special educators also asserted that while drafting a law for persons with disabilities, the Indian cultural context is highly relevant, and argued for supported guardianship for certain categories of disabled people. In fact, some felt that “it is the safest of safeguards and should be included in the law.”

In contrast to persons with intellectual disabilities, being represented mainly by parents and caregivers, people with psycho-social disabilities demanded complete legal capacity, based on their personal experiences of being subjected to guardianship, suspension of their choices and decisions, which sometimes served to further marginalize them because of the Mental Health Act (MHA) 1987. The redrafting of the chapter on legal capacity by the parents’ groups, service providers and rehabilitation professionals created an atmosphere of distrust between these groups, seriously affected by the clause of legal capacity. Self-advocates living with psycho-social disability also questioned the fact that the email with the redrafted version deliberately left out members of this group. As one of the co-convenors of the group on legal capacity, D., a self-advocate and founder of an organization working with persons with psycho-social disability wrote, “the most public fact known about me and about my views on legal capacity... I found it quite curious that your long list did not include my name, nor for that matter, did it include any others .... who would have a contest with you on your discriminatory views on Legal Capacity.”

What these self-advocates categorically called out was the support that some activists with disabilities extended to the parents’ groups and they expressed reservations about the legal capacity of particular categories of persons with disabilities, which was interpreted as a political move underscoring the hierarchy among disability categories. While the parents’ groups had referred to the powerful voices within the disability movement, these self-advocates pointed to the same intra-disability group power hierarchy as discriminating against them. As D wrote, “Some disabled people’s organizations highest in the pecking order join hands with caregivers’ groups and want to look down upon us who are the lowest, mostly put away in institutions or under house arrest because of restrictions on capacity and deprivation of liberty.”

This comment was in reference to another consultation where some blind lawyers argued for guardianship of persons with psycho-social disabilities as they doubted the ability of such persons to exercise legal capacity.

As the redrafting was done with the active support of a blind lawyer activist with proximity to government departments, with the consent of some other disability activists with blindness and locomotor disability present at the consultation, self-advocates living with psycho-social disability pointed to the ways in which disability activists were also influenced by the prevalent socio-cultural attitudes, and sought to prevent certain categories of disabled people from making choices and taking decisions. “... again and again we are supposed to ‘prove’ our rationality to people who are carrying the legal and societal biases ... 200 years of paternalistic control over PLMI and mentally disabled people has led to over determination of power from vested groups including care givers. So, the blind and the wheel chair bound are welcomed in this discussion, but those crazy folks... NO, not them. What do they know anyway? They are incapable.”

The angst expressed in these words reflects the ways in which the power hierarchy among disability categories operates, where influential blind and locomotor disabled activists counter assertions of capacity for choice and decision-
making by some and offer differential rights of legal capacity to different groups of disabled people.

For activists with psycho-social disabilities, the moment of reckoning had arrived with the drafting of the new disability law, when they decided to vociferously highlight the process of marginalization within the category of disability. The process of “othering” within the disability movement on the question of legal capacity reflects social attitudes that deny respect to certain categories of impairments, along with the powerlessness of othered groups, herein primarily persons with intellectual, psycho-social and multiple disabilities, whose voices were being represented by parents or were sought to be stifled with aspersions of incapacity. People with psycho-social disabilities argued that denying the possibility of legal capacity to all people with certain kinds of disabilities is an infringement of rights, as it is possible that only a small group of people with the severest disabilities will require assisted decision-making. When some locomotor disabled and blind activists argued that full legal capacity for certain groups had to be examined in the light of the socio-cultural and historical context of India, D. responded, “They said that we are being futuristic in asking for full legal capacity. I asked them whether they thought they were being futuristic when they asked 10 years back for accessibility or for Braille in the PWDA. Where did culture and history of the great India go then?” For many of these self-advocates, a “futuristic” law that would put in place mechanisms to enable all groups of people to exercise legal capacity through a series of staggered measures, moving from different degrees of dependence to varying forms of exercise of legal capacity.

The debates revealed much about the ways in which discussions on legal capacity got framed and the differential interpretation of citizenship rights for different groups of persons with disabilities. The varying ways in which different groups understood, discussed, debated and made recommendations for legal capacity for persons with disabilities exposed the group dynamics and politics that pitted dominant disability groups against one another. Further the clubbing together of psycho-social disabilities with intellectual and developmental disabilities for denial of legal capacity prevents one group from asserting legal capacity, while denying the other the possibility of assuming legal capacity. These debates also brought to the fore the core issue of voice, of who can purport to speak for the disabled—if survivor-self-advocates are more suited to deciding the mechanisms of legal capacity, what about parents’ groups? While recognizing the validity of the arguments of persons with psycho-social impairments in highlighting the ways in which their decision making is affected by the notions of in/sanity by the caregivers specifically and society in general, the concerns of caregivers of people with intellectual and developmental disabilities needed to be addressed comprehensively. Though the assumptions of complete lack of decision-making needed to be challenged, the fears of the caregivers within a zero-support administrative and community system brought up important and valid questions around care and financial support.

Conclusion

Rights legislations have been viewed as instruments to shift the underlying power dynamic between citizens and the state. In India, rights-based legislations grant power to the underprivileged majority in the face of an elitist political system (Dreze 2010),
and become a critical tool that citizens can mobilize to place claims on the state, which frames policies restricting access to resources. While the new civil rights paradigm recognizes the socio-political origins of the discrimination against persons with disabilities, the process of framing policy in India has remained confined to a vision of citizenship that restricts participation to entitlements, and makes little provision for enabling self-determination, thereby limiting opportunities for further levels of participation. In terms of provisions and entitlements, the arguments over reservations and criteria for qualifying for such provisions demonstrate this schism among the disability activists themselves. As Albrecht (2002) has pointed out, the disability rights movement is contentious due to a lack of common discourse, discrepancies in representation of disability within culture and society, beliefs about who is able to make effective contributions, and concern that the movement is made up of a privileged class of white, educated, visibly disabled persons. The debates around the framing of the new law engaged minimally with the removal of structural barriers and the rejection of the conceptions of social normality, which could lead to realigning the social relations of power.

In the light of the debates in the course of the process of framing the new disability law in India, it is evident that instead of envisaging a positive citizenship based on equality and emancipation for persons with disabilities, exclusion, hierarchy and social control defining insiders and outsiders (Armstrong 2006) have become a predominant exercise. Disability activists and the larger disability sector, influenced by the same ideas regarding people who fit in and can contribute in appropriate ways (Bellamy 2008), posited differing arguments on legal capacity for and against all persons with disabilities. The power hierarchies within the disability sector and the domination by specific groups of persons with disabilities claiming voice for all persons with disabilities, while representing certain groups as unable to exercise legal capacity, led to acrimonious debates around the structuring of privileges and restrictions based on an impairment category. While disability activists in the west and in India have always been wary of the ways in which gatekeepers impose restrictions on capacity and liberty for certain groups of persons with disabilities, these debates, on the one hand, witnessed a challenge to the traditional power equations and, on the other, a reassertion of powerful voices from among the disability activists, intended to silence forever particular groups of persons with disabilities. The discourse of disability rights was sought to be dominated by disability activists with powerful identity markers—impairment category, educational attainments, legal expertise and perceptions of legal capacity. This dominance and usurping of the voices of the other groups within the disability categories was contested by people with psycho-social disabilities, as a reflection of paternalistic control by vested groups including caregivers. On the other hand, people with intellectual impairments were reduced to a voiceless minority, represented primarily by their parents' groups with specific demands of protection and care. The idea of protection embedded within the concept of disability is thereby framed differentially in the Indian context—while the voices of caregivers is evidently muted within the disability movement; yet, on issues of legal capacity, decision making and control over financial resources, either they are suspect (as in case of people with psycho-social disabilities) or they take over entire control (as in case of intellectual and developmental disabilities). While the caregivers are definitely positioned within the power hierarchy, they slide up and down in terms of the group against which they are referenced. This relative positioning also negates the possibly positive role played by
these caregivers in the everyday lives of many people with disabilities, across all
disabilities. The contradiction between legal capacity and protection, between voice
and representation, between power/knowledge and marginalization has reinforced the
internal hierarchies of persons with disabilities, among whom the most
disenfranchised are the deaf, people with psycho-social disabilities, and poor people
from rural areas with disabilities. This entire discourse framing was, however, only in
terms of different impairment categories and to some extent gender, while completely
ignoring the impact of region, caste, community, religion and other identity markers
that are so important in India. In fact, there is very little research to illuminate the
situation and specific concerns of persons with disabilities from other caste groups, or
different religious and ethnic communities in India.

The framing of disability policy in India in consonance with the UNCRPD itself
generated a discourse around access to citizenship for persons with disabilities in a
socio-cultural context where dependence and independence are leveraged in multiple
ways for all communities, including marginalized groups such as the disabled. The
varied voices within the disability sector and its reluctance to engage actively with the
state to change the social environment revealed the role that structures of civil society
play—one greater than that played by political structures—in reproducing dominant
social norms and beliefs (Buttigieg 1995). The multiple players within the disability
sector, all representatives of civil society, reflected in different ways the dominant
ideologies, the accepted and uncontested cultural norms of able-bodied functionality,
performance and capacity. Thus, their discourse, specifically on legal capacity, sought
to establish and maintain, through everyday practices and public and civil society
institutions, the existing social order as natural and inevitable, by imposing values that
explained and justified the subordination of particular groups of persons with
disabilities. The reassertion of social ideologies around disability structured the
discourse and attempted to prevent local assertions for alternative discourses to
emerge and gain legitimacy, by systematically dismissing their claims. While the
disability sector was willing to accommodate the claims of other groups for inclusion
within the disability category, they also lobbied to maintain their hegemony by
representing disability both as a limitation of the mind and body within a particular
social context and the social experience associated with it, using this to leverage rights
claims differentially and ignoring the possibility of progressive realization of
citizenship rights by persons with disabilities. In this entire project of framing the
inclusive disability policy, the discourse revolved around exclusions—of disabled
people from larger systems and structures in India and of particular groups within the
larger disability community.

BIBLIOGRAPHY

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NOTES

1. I make a distinction between activists and self-advocates, keeping in mind that, the disability sector is diverse, comprising of non-disabled activists, disabled activists and self-advocates. Self-advocates are primarily persons with disabilities highlighting their concerns, which may not be evident to other disabled activists.


3. Email communication March 11, 2011


5. Email communication December 25, 2010


7. Email communication March 10, 2011

8. Email communication March 10, 2011

9. Email communication March 11, 2011

10. Email communication March 10, 2011

11. Email communication March 10, 2011

12. Report of consultation received through email communication

13. Email communication March 10, 2011

14. Email communication March 11, 2011

15. Email communication March 11, 2011

16. Email communication March 11, 2011
ABSTRACTS

The neo-liberal discourse of rights focuses on rights-based legislations and empowers citizens to place claims on the state. The push toward a rights-based approach in India by disability activists sought to shift the underlying power dynamic between citizens and the state through legislation. However, such rights-based discourses underplay or negate intra-group power politics that influence claims to rights and entitlements. This paper attempts to explore the ways in which disability groups in India engaged with the concept of citizenship in the debates prior to the passage of the Rights of Persons with Disabilities Act 2016. As citizenship creates whole categories of people who are subject to the government’s authority, an attempt will be made to see how actors within the rights movements interacted among themselves and with the state, to ensure welfare provisions as well as citizenship rights for different groups of people from different impairment categories.

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Keywords: disability rights, law, citizenship, power, legal capacity

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