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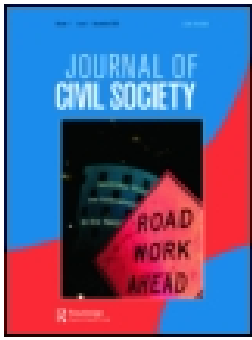
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# An institutionally Ableist State? Exploring civil society perspectives on the implementation of the convention on the rights of persons with disabilities in India

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## ABSTRACT

In response to international concerns about ongoing rights violations, this benchmark study analyses the situated knowledge of civil society organizations and examines their discourse on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in India. The findings show that Persons with Disabilities continue to experience rights-denial, and institutional ableism resulting in barriers to shaping policy and accessing social welfare. These are real challenges owing to their systemic nature. Crucially, they relate to the public policy-making process itself and stem from a failure on the part of successive post-2007 governments to put in place a comprehensive strategy for implementing the CRPD. In turn, this is indicative of an ongoing disconnect between state and civil spheres that hampers effective implementation and explains the endurance of the Medical Model of Disability across the country.

## KEYWORDS

Persons with disabilities; civil society; institutional ableism; rights; welfare; discourse; India

## Introduction

This study presents analysis of civil society organizations' (CSOs) discourse on the human rights situation in India for persons with disabilities (PWD) 2012–17. This is an appropriate locus of enquiry on number of grounds. First, because many of the country's 26.81 million persons with disabilities continue to be subject to discrimination and ongoing rights denial. As one campaigning organization complained, 'Human rights violations in the context of disability are prominent in Indian society ... disabled Indians are treated as second-class citizens and are forced to confront segregation, discrimination, barriers and stereotypes' (Banglar Manabadhikar Suraksha Mancha, 2016, p. 5). In a similar vein, the United Nations noted its ongoing concern at: 'legislation, public policies and practices that discriminate against persons with disabilities – in particular: guardianship, institutionalization, psychiatric treatment and segregated community services based on disability, and negative perceptions' (United Nations, 2019, para 5).

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Second, the present study's focus is apposite because of political failure to address rights violations. Governing elites in India remain largely apathetic. Underpinning this malaise is the fact that 'India does not differentiate between impairment, disability or handicap and uses the terms synonymously, with a firm cultural grounding in destiny' (Ghai, 2015, p. xvii). In the following discussion we show how this is part of widespread institutional ableism in the country. This occurs when social groups and social structures value and promote certain abilities over others (Chaney, 2015; Wolbring, 2008). It is a form of discrimination based on 'the perception that being able-bodied is the normal human condition and is superior to being disabled' (Hehir, 2005, p. 7). Institutional ableism falls within the realm of neo-institutionalist analyses of the policy process (Lowri, 1961). Over recent years it has gained increasing currency in social science (Gabel & Danforth, 2008; Kumari Campbell, 2009). It is different to individual prejudice against persons with disabilities by virtue of its systemic, structural nature (Fierros, 2006).

Third, this article's focus is appropriate because of demographic factors; specifically, the growing prevalence of multiple disabilities among older people in India (Maikho Apollo Pou & Goli, 2013, p.63). The 2011 census of India gives an idea of the scale of the policy-challenge that this presents. It revealed that the number of people aged over 60 years had reached 103.8 million, with 11.3 million aged over eighty. Forecasts suggest a further significant demographic shift such that by 2050 there will be 323 million people over the age of sixty. This has major implications for the future number of people with disabilities requiring health and social care (Saikia et al., 2016).

Fourth, the current focus on PWD is necessary because, in contrast to Western academia, the issue of disability has not been adequately studied in India. This failure runs the risk of reinforcing notions of sympathy and charity rather than the scholarly exercise of criticality and attention to disability as a human rights issue (Ghai, 2018a; Kumar & Dwivedi, 2017).

Fifth, the following analysis is timely because it is little over a decade since India ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), thus making it an appropriate point to assess progress. Crucially, and in a manner that resonates with the Social Model of Disability (see below), Article 33 of the CRPD requires a participatory approach to implementation; one not solely driven by state bureaucracies but involving civil society organizations. However, speaking of the disability rights movement in India, Bhambhani (2018, p. 21) says, 'the movement in India needs to learn from, adapt to, engage and forge alliances with other movements'.

Together these factors constitute the underlying rationale for this benchmark study of the vital, early phase of CRPD implementation. This is a key window when countries begin to address their Convention obligations. In the language of historical institutionalism it is a critical juncture (Capoccia & Kelemen, 2007); a point at which member states can break the path dependency of past discriminatory and oppressive practices and implement new rights-based approaches. Accordingly, by analysing civil society UPR submissions, the following discussion provides insight into the ability of policy and politics in India to adapt and conform to the CRPD.

In conceptual terms, the present locus of enquiry is a topic deserving of attention because contemporary thinking about disability in India remains rooted in the Medical Model of Disability, instead of embracing a more sophisticated view of PWDs' rights as social, cultural and political phenomena (Ghai, 2015). The UN (2019,

para 5) concurs, noting that amongst its principal concerns is, ‘the prevalence of the medical model of disability in legislation, public policies and attitudes concerning persons with disabilities ... and in the misunderstanding of disability, including leprosy, as solely a biological condition requiring prevention and rehabilitation’. As Reiser (2006) explains, the outdated Medical Model regards the disabled person as the problem. Typically, attention centres on impairment and there is a discourse of cures, normalization and science. In contrast, the CRPD is predicated on the Social Model of Disability. This explains disability as a function of the inequalities and discrimination that prevent PWD taking part in the normal life of the society (Shakespeare & Watson, 2001). The difference between the two models has major implications for the nature of contemporary welfare provision and whether social policy in today’s India promotes dependency or empowerment and independent living.

The data for the present study are drawn from civil society organizations’ reports submitted to the third UN Universal Periodic Review (UPR) in 2017 (and covering the preceding five years) (see Methodology). Introduced in 2006, the UPR is the five-yearly evaluation process associated with UN rights treaties that is conducted under the auspices of the Office of the High Commissioner for Human Rights (OHCHR).

In summary, the current research aims are: 1. To understand what CRPD implementation issues CSOs identify and, what priority they attach to them; 2. To understand CSOs’ use of language (or framing) in their UPR discourse; and 3. To reflect upon what the study findings tell us about CRPD implementation and the associated implications for PWD in India today. Accordingly, the remainder of the article is structured thus: following an outline of the research context, attention centres on social theory, and the study methodology. This is followed by the research findings in three sections – the first examines the policy issues highlighted in the CSO UPR submissions; the second CSOs’ framing in their reports to the UN. In the third, the findings are discussed in the context of extant research with a focus on what they tell us about CRPD implementation and the implications for PWD in India today. Finally, steps necessary for future progress are outlined in the conclusion.

## Research Context: Persons with Disabilities in India

Extant research points to widespread prejudice towards PWD in India. Existing studies have variously concluded that cultural and religious beliefs underpin negative attitudes towards disability leading to widespread attitudinal barriers (Deepak et al., 2014). Moreover, Ghai (2018b, p. 245) describes the gendered dimension to this discrimination: Indian ‘society ... accepts the able-bodied norm [and] subjects disabled girls and women to the most inhumane treatment possible. Thus, right from childhood, disability imposes a subordinate status on them, and increases the likelihood that their rights will be ignored’. In a similar vein, writing of the societal barriers facing disabled people, Chopra (2013, p. 809) provides a powerful account of the extent of contemporary rights-denial:

At times disabled persons have to face neglect and abhorrence from their own family members; they are not considered a basic unit of society. Infanticide of disabled persons is not uncommon in India. Disabled persons are most often left behind at home and conditioned to abstain from participating in social events and gatherings ... Society sometimes looks down and ostracizes them to avoid incurring any liability

towards them since they are considered to be suffering for their previous birth deeds. Disability also causes social stigma... They are subjected to violence, abuse, prejudice, or disrespect because of their disability.

Although the Indian Constitution does not set out comprehensive rights for PWD, a number of Articles potentially offer a degree of legal protection. For example, Article 41 notes that 'the State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of ... disablement'. Yet it remains the case that in the domestic legal code, rights for PWD remain fragmented and incomplete. Much hope now centres on two recent enactments, the Rights of Persons with Disabilities Act, 2016 and the Mental Healthcare Act, 2017. The former became operational in 2017 and, according to its preamble, it is 'an Act to give effect to the United Nations Convention on the Rights of Persons with Disabilities and for matters connected therewith or incidental thereto'. However, whilst welcoming the new statute, the UN (2019, para 11) also stated its concern at, 'the exceptions to the anti-discrimination clause in Section 3.3 ... allowing for discrimination against persons with disabilities under certain circumstances'.

In addition to the constitution and domestic legal code, India's Sustainable Development Goals (SDGs) and '2030 Agenda for Sustainable Development' are intimately concerned with PWD rights. For example, SDG 4 'Guaranteeing equal and accessible education', SDG 6 'Promoting inclusive economic growth, full and productive employment', SDG 10 'Emphasizing the social, economic and political inclusion of persons with disabilities', and SDG 11 'Creating accessible cities ...' and SDG 17 requiring the collection of 'disability disaggregated data'.

## Social Theory

Co-working between CSOs and government is a foundational element in the CRPD. For example, Article 1 requires states to ensure PWDs' 'full and effective participation in society on an equal basis with others' and, Article 29 requires that PWD have an equal opportunity to participate in public decision-making, including policy-making. Elsewhere, Article 33 asserts 'Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the [CRPD] monitoring processes'.

Such participation and co-working, is also supported by a number of strands of social theory. For example, complementarity theory (Klijn & Skelcher, 2007) emphasizes how politicians seek to deal with complexity by using CSO networks in order to increase external involvement in policy implementation. This not only strengthens input legitimacy – in other words, the democratic credentials of public policy – but also potential policy efficacy through the pursuit of shared goals. In definitional terms, it should be noted that the term civil society refers to associational activities involving non-governmental organizations, charities, pressure groups, social movements, community groups, and campaigning organizations (Keane, 1988). In turn, the participatory approach to public policy-making set out in the CRPD is also integral to the deliberative democracy paradigm (Cohen, 1997). In addition, Habermas' Theory of Communicative Action (Habermas, 1994, pp. 7–8) validates the current focus on the deliberative input of CSOs in order to secure PWD rights. Notably, he alludes to how:

An autonomous basis in civil society, a basis independent of public administration and market-mediated private commerce, is assumed as a precondition for the praxis of civic self-determination. This basis preserves political communication from being swallowed up by the government apparatus or assimilated to market structures.

In summary, both the policy framework associated with the UPR and the CRPD, and diverse strands of theory validate this study's research design by underlining the need to examine not only the actions of political elites and state bureaucracies, but also the views of civil society organizations.

## Methods

In methodological terms, the current approach offers a transferable discourse-based technique for studying rights implementation. It has two parts. The first centres on understanding the key CRPD implementation issues across public policy areas as identified by CSOs, and the second explores CSOs' use of language in their UPR submissions.

The dataset used in this study is derived from state and civil society submissions to the UN Universal Periodic Review (UPR). It is a singular, rich source that advances understanding of the role of civil society as a political space for resistance to oppression and the realization of PWD rights. As noted, the UPR emerged in the wake of the 2006 UN General Assembly resolution (60/251) and is conducted under the auspices of the Office of the High Commissioner on Human Rights (OHCHR). Its proponents argue that it provides the opportunity for each state to outline the actions they have undertaken in order to promote human rights. To do this it makes provision for civil society input. The policy guidance is unambiguous: 'the UPR should ensure the participation of all relevant stakeholders, including non-governmental organizations' (OHCHR, 2011, p. 7).

The present use of discourse analysis is underpinned by diverse strands of social theory, including the interpretive school of policy analysis (Yanow, 1999) and social constructivism (Kukla, 2000). Both place emphasis on values, beliefs and interpretations relevant to a given policy issue (Eden & Ackermann, 2004). The epistemological grounding of the present research is standpoint theory. In particular, the notion of situated knowledge (Stoetzler & Yuval-Davis, 2002). This states that first-hand accounts (in this case, from organizations representing PWD affected by oppression and discrimination), are a valuable complement to records of jurisprudence and institutional proceedings.

The data for the present study are drawn from 72 civil society organizations' reports submitted to the third UN UPR in 2017 (and covering the preceding five years). The aforementioned number of CSO submissions under-reports the breadth of civil society input for many are joint submissions authored by broad coalitions of standalone organizations (one, for example, is made up of 181 CSOs. The length of the reports varies. The 26 submissions from single civil society organizations were typically 2000 words in length (e.g., Access Now). Whilst the 46 joint submissions from alliances and networks were typically 15,000 words, although those with Annexes were up to 30,000 words in length (e.g., Housing and Land Rights Network, India). Overall, the corpus of civil society organizations' UPR submissions is a rich data source that totals 750,000 words.

Examination of issue-salience was done using content analysis (Neuendorf, 2002) of text-readable electronic copies of the UPR submissions. This was a two-stage process. The final dataset was a sub-set of the UPR corpus comprised all text referring to disability

issues as identified by key signifiers (including, disability, disabled, blind, visually impaired, deaf and so on). In turn, a mode of content analysis taken from electoral studies was applied to the dataset. This sub-divided the text into quasi-sentences. The latter are arguments or verbal expressions of one political idea or issue (Volkens, 2001). Splitting sentences in this way controlled for long sentences that contained multiple policy ideas. Thematic analysis identified the number of references or quasi-sentences related to each policy topic which were then logged into a database. This allowed a breakdown of the level of attention to (and therefore an indicator of prioritization of) policy topics amongst competing issues related to PWD in the UPR discourse.

In addition, a further phase of the analysis centred on framing. This is the language used by policy actors. Effectively it is a 'schemata of interpretation' (Goffman, 1974, p. 27) and informs us about the intrinsic meanings in the text, as well as actors' critical thinking in relation to policy ideas and rights observance. A deductive approach to framing was employed (see for example, D'Angelo & Kuypers, 2010; Dirikx & Gelders, 2010). The frames were derived from the CRPD (*inter alia*, rights, access, exploitation, violence & abuse; discrimination; care/support/help/assistance). The dataset was coded according to the frames occurring in the in the text. CSO discourse linked to each frame was then added to the database. As the foregoing describes, the analysis involved decontextualization (or segmentation) of the UPR reports into pieces of information and their subsequent recontextualization to interpret the findings.

In order to enhance the accuracy and credibility of these processes we followed the key assurance techniques outlined by Morse et al. (2002) and Nowell et al. (2017); namely, researcher triangulation on reliability and validity. Thus a research assistant checked the identification and coding of the quasi-sentences in relation to the different policy topics and frames in the database. The author and research assistant disagreed in five instances overall (in three instances the author had miscategorized discourse concerned with 'Law/Administration of Justice' – including it in the miscellaneous section; and in two instances the author had included instances of stigma in the discrimination frame). These differences were resolved by discussion between the author and the research assistant. Following the latter's intervention each of the cases was reclassified in the database. As noted, researcher triangulation was also used with regard to recontextualisation. The research assistant checked all of the exemplar quotes in the article against their original classification in the database. She then re-read the quotes in the context of the original documents to check that they were a valid and accurate illustration of the policy issue or frame. In this regard there was no disagreement between the researchers. Attention now turns to the study findings.

## Study Findings

### **1. Policy Areas/Issues and CRPD Violations Highlighted in the CSO Discourse**

In this section we address the first research question; namely, what CRPD implementation issues do CSOs identify and what priority do they attach to them? The principal finding that emerges is a raft of (non-discrete) rights violations spanning policy areas. This is particularly important because, as noted, the present marks a critical juncture at the beginning of CRPD implementation and, over coming years, the country faces a



**Table 1.** Issue salience: level of attention to different policy areas in CSOs’ third cycle UPR submissions (*N* = 310).

Policy Area/Issue	CRDP Violation Identified in CSO Discourse	Percentage of all quasi-sentences
Education	Article 24	29.0
Law/Administration of Justice	Articles 4 and 13	19.4
Intersectionality in Public Policy	Preamble, Article 6	12.9
Employment/socio-economic inequalities	Article 27	11.9
Healthcare	Article 25	9.4
Housing	Article 28	7.1
Forced Sterilization	Article 25, (d)	2.6
Data on PWD	Article 31	2.6
Misc. <sup>a</sup>	Various	5.2

<sup>a</sup>Includes raft of policy issues including: legal capacity issues, social care and transport.

significant rise in the number of PWDs owing to an ageing population. As the following discussion reveals, the findings do not augur well. CSOs repeatedly express their frustration at the government’s failure to address shortcomings identified during the Second Cycle UPR. These were formally noted by the Indian Government in 2012. CRPD violations receiving most attention were in the areas of: education (accounting for almost a third of all quasi-sentences, 31.5%); followed by law (21%), intersectionality (14%) and employment (12.9%) (Table 1).

In terms of language use, the following analysis also reveals how the CSO discourse emphasises a range of frames that collectively underline the need for India to move away from the outdated Medical Model and embrace the Social Model of Disability. The dominant frames include: rights, (anti-)discrimination, participation overcoming exploitation, and access, independence/(de-)institutionalisation (Table 2). Together these total almost three-quarters (74.5%) of the CSO discourse.

Attention now turns to explore the civil society discourse in further detail; first, with attention to policy areas and associated CRPD violations – followed by analysis of framing. This is organized by considering each policy area and frame in turn. In the third section this study’s findings are then discussed in the context of extant research on disabled people’s rights and consideration is given to what they tell us about CRPD implementation and their implications for PWD in India today.

**Table 2.** Level of attention to different frames in CSOs’ third cycle UPR discourse (*N* = 310).

Frame	Associated CRDP Violation Identified in CSO Discourse	Percentage of quasi-sentences
Rights	Article 28	21.0
Access	Preamble, Article 3	13.7
Exploitation, violence & abuse	Article 16	13.7
Discrimination	Article 3	9.2
Care/support/help/assistance	Articles 25, 26, 13, 24	8.9
Exclusion/marginalization	Preamble,	7.6
Independence/empowerment/(de-)institutionalization	Article 9	6.7
Protection	Preamble, Articles 27, 28	6.1
Equality	Article 3	4.5
Needs	Article 4, 19, 26	3.8
Participation/representation	Article 29	2.5
Stigma, Stereotypes and Prejudices	Article 8	2.2

### ***i. Education***

Since ratification in 2008, India has been subject to CRPD obligations on the right of persons with disabilities to education without discrimination (Article 24). However, the present analysis shows rights violations in education to be the first-ranked policy issue in CSOs' submissions to the UPR (almost a third of all discourse, 29% of quasi-sentences).

Civil society organizations' submissions to the third cycle UPR reveal little progress since the second cycle UPR in 2012. The discourse points to manifold reasons for this, including: a lack of political will to address rights violations, a failure to uphold the law, and a significant mismatch between the scale of rights violations and the amount of resources authorities are willing to allocate in order to address them. The discourse also repeatedly highlights a gender divide and the need to address the causes of the low enrolment rate of girls with disability. Thus, one CSO complained:

Despite the enactment of the law on right to education, discrimination, particularly discrimination that affects girls, marginal groups, and persons with disability continues. Inadequate number of teachers, teacher absenteeism and poor quality teaching and learning remain. (HAQ: Centre for Child Rights, 2016, p. 2)

A core trope in the CSO discourse was a general failure to comply with the Right of Children to Free and Compulsory Education Act (2009). Section 3 is explicit: 'a child with disability ... shall, without prejudice have the same rights to pursue free and compulsory elementary education'. Amongst the issues highlighted by CSOs were the fact that specific services for children with disabilities continue to be unavailable to the majority, and that budgetary allocations for programmes related to children with disabilities are poorly funded and unable to cater the needs of such children. Furthermore, the discourse revealed how private Schools are largely ignoring the minimum standards set out in the Act, including provision of a trained teacher, improvements in physical access to school premises and delivering a minimum number of instructional hours each year.

### ***ii. Law and the Administration of Justice***

The second-ranked policy area was law and the administration of justice (21% of quasi-sentences). Here the authorities are bound by CRPD Article 4 requiring new legislation or modifying or abolishing existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities. Furthermore, under Article 13 government is required to ensure effective and equal access to justice for persons with disabilities. Analysis reveals that the Third Cycle CSO discourse centred on two broad areas: shortcomings in the legal code and, failings and maladministration in the criminal justice system. Writing about the Rights of Persons with Disabilities Act, 2016, the Indian Government in its UPR submission said, 'this law aims to facilitate greater access to public spaces, education, employment, and healthcare, and the integration and protection of rights, particularly of persons with mental illness or disability' (GoI, 2017, para 139). However, whilst some CSOs gave the Act a cautious welcome, many were critical. For example, one noted,

The Act addresses a certain portion of the society instead of guaranteeing civil and political rights to [a] wider section of the disabled people ... There is a definite need to review the

existing legislative framework in India to examine whether it adequately promotes the rights contained in the Convention [CRPD]. (AALI et al., 2016, p. 3)

Others called for a more progressive anti-discrimination law to address all types of discrimination that is enforceable against private enterprises and transnational actors. Further calls were for an amendment to the Disabilities Act to protect women and girls with intellectual disabilities from forced sterilization.

As noted, failings and maladministration in the criminal justice system was the second strand in the civil society discourse. It is typified by CSOs' calls for the policy on correctional homes to be revised in relation to prisoners with disability. Specific demands include that the homes be rebuilt to a higher standard than at present, and that civil society groups and mental health activists be allowed to visit PWD in prisons and provide legal, social, psychological services. Others highlighted that, despite reforms introduced in 2012 to help women and girls with disabilities who experience sexual assault, the reality is government has yet to put in place a systematic monitoring mechanism to ensure that state governments (the bodies tasked with implementing these laws) work cohesively with the federal government to adequately budget for their implementation. As one CSO put it, the result is that, 'women and girls with disabilities continue to face barriers to accessing justice' (Human Rights Watch, 2016, p. 4).

### *iii. Intersectionality*

Article 6 of the CRPD requires that government recognizes that women and girls with disabilities are subject to multiple discrimination, and takes measures to ensure their full and equal enjoyment of rights and fundamental freedoms. The need for an intersectional approach (Crenshaw, 1991; Hooks, 1984) to public policy affecting PWD is the third-ranked issue (14% of quasi-sentences) in the civil society UPR discourse. Much of the discourse is critical of government's tendency to overlook disabled people's multiple identities. Particular attention is given to Article 6 violations and how women face multiple layers of discrimination with regard to access, control, ownership, and inheritance of land, property, and housing. According to one CSO, 'the worst marginalization is experienced by women who are living with mental illness, HIV/AIDS, [and] disability' (Housing and Land Rights Network India, 2016, p. 9). A further theme in the discourse centres on the need for government to draw upon data disaggregated by income, sex, age, caste, ethnicity, migration status, disability and geographic location in order to develop public policies based on intersectionality and plan customized interventions rather than rely on a one-size-fits-all approach. For its part, the UN (2019, para 11c) has also expressed similar concerns to the Indian Government about, 'the absence of measures to combat multiple and intersecting forms of discrimination against ... persons with disabilities'.

### *iv. Employment/Socio-economic Inequalities*

Article 27 of the CRPD asserts that government shall recognize the right of persons with disabilities to work on an equal basis with others. Moreover, as noted, the constitution says that the state, 'shall make effective provision for securing the right to work, to education and to public assistance in cases of ... disablement ...' (Article 41). In its UPR submission, the Indian Government said it, 'has launched and strengthened various

schemes, most of them under the umbrella of the Unorganized Workers (Social Security) Act, 2008'. It continued, 'Under the flagship National Social Assistance Programme (NSAP), five schemes provide monetary and other assistance to ... persons with disabilities' (GoI, 2017, para 72).

However, the present analysis suggests that such interventions are failing to prevent Article 27 violations because employment/socio-economic inequalities was the fourth-ranked policy issue (12.9% of quasi-sentences) in CSOs' Third Cycle submissions. Existing work shows how socio-economic inequalities are particularly linked to the intersection of disability and ageing (Maikho Apollo Pou & Goli, 2013), yet for all age groups the civil society discourse points to widespread and systemic barriers to PWDs' employment operating over the life-course, as well as how this is linked to education. A key concern in the UPR submissions was how children with disabilities in rural areas are often excluded from the education system due to physical and/or social barriers. In consequence they receive no education at all. For those that do manage to attend CSOs also highlighted high drop-out rates. In turn, the UPR submissions alluded to how the lack of motivation and encouragement to attend school leads to increasing unemployment and poverty for disabled people. Thus one CSO observed that 'the employment rate both in terms of wages and self-employment is less than 10% for persons with disabilities due to negative attitudes, inaccessibility and unaffordability of technology and transport systems' (Action Aid Association, 2016, p. 6).

#### **v. Health**

Article 25 of the CRPD asserts that persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. Notwithstanding this, Article 25 violations were the fifth-ranked policy issue (10.1% of quasi-sentences) in the civil society UPR submissions. The discourse shows how CSOs feel there has been little progress since the second cycle UPR. At that time, writing about policies and services for persons with intellectual disability, Girimaji and Srinath (2010, p. 443) underlined the prevalence of the Medical Model of Disability in healthcare. They concluded that, 'issues such as awareness, advocacy, appropriate formulation, implementation and ongoing evaluation of programmes, and protection of [PWD] rights need greater attention'. Amongst the myriad issues highlighted in the third cycle data was states' failure to comply with their constitutional duty to all citizens – including PWD, to raise the level of nutrition, healthcare and standard of living. A further core trope was authorities' failure to make healthcare more accessible to disabled people.

#### **vi. Housing**

The right of persons with disabilities to adequate housing without discrimination on the basis of disability is set out in Article 28 of the CRPD. Yet Article 28 violations were the sixth-ranked issue in the CSO discourse (7.7% of quasi-sentences). It is a further example of a policy area where the CSO discourse reveals government failure to address the inequalities identified in the previous UPR cycle. Almost a decade ago, the UN recommended that the Indian Government, 'ensure better protection for persons with disabilities' (United Nations, 2012, p. 26). Yet the Third Cycle data reveal how access to housing and basic services is still a struggle for PWD. The CSO discourse notes that whilst several housing schemes contain provisions for persons with disabilities, including

preferential allocation, these are dwarfed by the actual scale of demand. Others alluded to tensions between the state's human rights obligations and neo-liberal approaches to the economy. Thus, one CSO complained that:

India's macroeconomic growth paradigm promotes homelessness, forced evictions, land grabbing/alienation, and displacement. In the last four years, several cases of violations of housing and land rights have been reported across the country; the worst affected include persons with disabilities. (Housing and Land Rights Network India, 2016, p. 4)

### ***vii. Forced Sterilization***

Forced Sterilization remains a key violation of CRPD Article 25. It was the seventh-ranked policy issue. Once again, the civil society discourse alluded to government failure to respond to earlier UN recommendations. In particular, CSOs highlighted the particular vulnerability of women and girls with intellectual disabilities. They also condemned government's failure to adhere to its own policies, such as the Guidelines on Female Sterilization issued in 2005.

### ***viii. Data***

Article 31 of the CRPD requires government and public authorities to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention. Notwithstanding this, violation of Article 31 was the eighth-ranked policy issue (2.2% of quasi-sentences). The third cycle submissions repeatedly highlighted how disability data should be provided in all Indian Government reports submitted to the UN, including the UPR. CSOs also highlighted how such data should facilitate intersectional approaches to public policy-making for disabled people.

## ***2. Framing in the CSO Discourse***

Attention now turns to the second research aim, namely to explore CSOs' framing in the third cycle UPR submissions. The discussion includes a comparative perspective by referring to the Indian Government's UPR report.

### ***i. Rights***

Rights for PWD was the first ranked frame accounting for over a fifth of quasi-sentences (21%). In contrast to the raft of rights for PWD set out in the CRPD, the Indian Government's Third Cycle UPR submission is brief. It is descriptive in nature and details its aspirations for the Rights of Persons with Disabilities Act 2016 ('This law aims to facilitate greater access to public spaces, education, employment, and healthcare, and the integration and protection of rights, particularly of persons with mental illness or disability', (Government of India, 2017, para 139).

In contrast, the civil society discourse is far more broad-ranging and critical. It questions whether the new Act achieves its goal of incorporating all of the CRPD into the domestic legal code. Notably, it condemns the Act's failure to address specific forms of violence faced by women with disabilities. A further key trope was the seeming disjuncture between the government's public spending commitments and its CRPD obligations.

In this regard a number of CSOs said the level of public spending on initiatives to enable and empower disabled people was inadequate.

### *ii. Accessibility*

Article 3 of the CRPD notes the need for PWD to have access to the physical, social, economic and cultural environment. However, the present analysis reveals that Article 3 breaches were the joint second-ranked frame in the CSO discourse (13.7% of quasi-sentences). CSOs variously refer to how public spaces and information are inaccessible to persons with disabilities. They also underline how authorities fail to keep or monitor data on differential access for disabled people. Amongst the CSOs' plethora of recommendations to the UN is a call to, 'Amend laws to ensure ... that the obligations on accessibility of public places are implemented in a time bound manner' (Joint Working Group on Human Rights in India, 2016, p. 5).

### *iii. Exploitation, Violence and Abuse*

Article 16 of the CRPD requires government to take all appropriate legislative, administrative, social, educational and other measures to protect PWD from all forms of exploitation, violence and abuse. However, Article 16 breaches are the joint second-ranked frame in the civil society submissions (13.7% of quasi-sentences). The CSO discourse reveals violence and abuse against disabled people to be widespread. A significant strand concentrates on violence in institutional settings and its effect on women and girls. Notably, the discourse highlights how persons with psycho-social disabilities suffer worst. A deeply troubling aspect of the discourse centred on how women with disabilities, particularly psychosocial and intellectual disabilities, face violence in the form of forced institutionalization. The submissions detail how, once institutionalized, they are often victims of several forms of violence, as well as inhumane and degrading treatment.

### *iv. Discrimination*

Tackling discrimination is one of the core general principles of the CRPD set out in Article 3. Yet the widespread prevalence of disability discrimination is evidenced by the fact that it is the third-ranked frame in the UPR discourse (9.2% of quasi-sentences). The civil society submissions detail its effect in all spheres of life, including public services. In particular, they highlight widespread discrimination against disabled pupils and students in schools and universities; as well as in access to housing and health care. Throughout the Third Cycle submissions there is repeated reference to state failure to respond to the earlier UN recommendations on tackling discrimination. For example, 'despite accepting recommendations during the second cycle to ensure better protection for persons with disabilities and the elderly, persons with disabilities remain particularly at risk of discrimination and violence' (Human Rights Watch, 2016, p. 4).

### *v. Care/Support/Help/Assistance*

Analysis of the civil society UPR submissions reveals widespread opposition to the dominant Medical Model of Disability in contemporary public service delivery and policy-making. In consequence 'care/support/help/assistance' is the fifth-ranked frame in the discourse (8.9 of quasi-sentences). In particular, CSOs called on government to

support community-based mental health and support services rather than creating new or refurbished mental health institutions. Others demanded that government provides specialized care to all children with disabilities in inclusive environments located in the neighbourhood where their parents, siblings and friends reside.

#### ***vi. Exclusion/Marginalization***

The preamble to the CRPD proscribes any distinction, exclusion or restriction on the basis of disability which interferes with human rights and fundamental freedoms in political, economic, social, cultural, civil fields. Notwithstanding this, the CSO data show that exclusion and marginalization of PWD continues to be a pervasive problem. It is the sixth-ranked frame in the UPR submissions (7.6% of quasi-sentences). Notably, many of the CSOs highlight how exclusion of children with disabilities from education is four times higher than the children belonging to other communities.

#### ***vii. Independence/Empowerment/(de-)Institutionalisation***

Article 9 of the CRPD requires government to take measures to enable persons with disabilities to live independently and participate fully in all aspects of life. However, the CSO discourse makes repeated reference to Article 9 violations. It is the seventh-ranked frame (6.7% of quasi-sentences). According to the discourse, government needs to develop and implement a de-institutionalization action plan for PWD based on the values of equality, independence, and inclusion. Others also highlighted the need to employ protective measures to prevent exploitation, violence and abuse of persons with disabilities in institutional settings.

#### ***viii. Protection***

Protection of PWD was the seventh-ranked (6.1 per of quasi-sentences) frame in the UPR submissions. The prominence of this frame reflects the endurance of the Medical Model in state practices, as well as civil society organizations' frustration at the limited pace of change. In particular, CSOs complained that despite the Indian Government accepting UN recommendations during the second cycle UPR on ensuring better protection for persons with disabilities, they remain particularly at risk of discrimination and violence. The UPR submissions made particular reference to how many PWD are locked up in overcrowded and unsanitary state mental hospitals and residential institutions. They also highlighted the limited opportunities for disabled people to challenge such institutionalization, notably because of stigma and the absence of adequate community-based support and mental health services.

#### ***ix. Equality***

Set out in Article 3, equality of opportunity is one of the core principles of the CRPD. It is also the eighth-ranked frame in the UPR discourse (4.5% of quasi-sentences). A core trope in CSOs' submissions was the need for authorities to recognize and ensure equal opportunities for children with special needs in education. Others complained that the Mental Healthcare Act 2017 fails to fully comply with the UN Convention on the Rights of Persons with Disabilities. Amongst many issues highlighted, CSOs noted how it does not recognize that people with disabilities enjoy legal capacity on an equal

basis with others in all aspects of life. Neither does it set out appropriate measures to provide the support they may require in exercising their legal capacity.

#### ***x. Needs***

Discourse framed in terms of meeting the needs of PWD was ninth-ranked in the discourse (3.8% of quasi-sentences). It centred on two main areas: the failure of policy and services to be appropriate and inclusive, and that government interventions are inadequate compared to the scale of the problem at hand. In particular, CSOs highlighted how significant further work was needed to make health and the judiciary disabled-friendly. Others underlined that comprehensive programmes should be implemented for legal, social service and health providers to be sensitive to the rights and needs of women living with disabilities. Another strand of the discourse noted that while several central and state government schemes attempt to address housing needs of PWD through reservation, discounted rates, and preferential allocations, these measures are not equal to demand and fail to address the many obstacles that people with disabilities have to confront.

#### ***xi. Participation/Representation***

Article 29 of the CRPD requires government to ensure that PWD can effectively and fully participate in political and public life on an equal basis with others. However, participation/representation is the tenth-ranked frame and the CSO discourse alludes widespread Article 29 violations. The core trope is the under-representation or exclusion of PWD in many decision-making forums, including public authorities and institutions of governance. A further problem is authorities' failure to monitor and address issues attached to the participation and representation of PWD. For example, one CSO complained that,

Disabled People remain out of political process, [and there is] no provision for reservations in elections, as compared to other marginalized sections. They are unable to vote with dignity as polling booths are largely in-accessible, dependency on others violates secrecy of voting. (Action Aid Association, 2016, p. 4)

Other CSOs referred to the need for affirmative action and demanded that the Indian Government promote the political participation of persons with disabilities in political and electoral processes by amending legislation and introducing quota systems in local, federal state, and country level elections.

#### ***xii. Stigma, Stereotypes and Prejudices***

Article 8 of the CRPD requires that government combats stereotypes, prejudices and harmful practices relating to persons with disabilities. However, the CSO discourse underlines continuing Article 8 violations. It also highlights the fact that 70 million disabled Indians are treated as second-class citizens and are forced to confront segregation, discrimination, barriers and stereotypes on a daily basis. According to one CSO, 'persons with disabilities remain particularly at risk of discrimination and violence ... in part due to stigma and the absence of adequate community-based support' (Human Rights Watch, 2016, p. 3).



***xiii. Framing in the Indian Government’s 2017 UPR submission***

Lastly, to conclude the present analysis of framing of PWDs’ rights in the Third Cycle UPR submissions attention now turns to summarize framing in the Indian Government’s 2017 report to the UN (Table 3). As noted, the section on PWD totals four paragraphs (out of 155) – or just 350 words in a 15,000 word document. Nevertheless, it provides a clear contrast to the civil society discourse, wherein three-quarters of quasi-sentences related to frames associated with the Social Model of Disability (Table 2). In the government submission over a half of frames align with the Medical Model. They variously emphasise: care, protection, exceptionality/need, assistance (rather than empowerment), vulnerability, and health.

***3. What This Study’s Findings Tell Us About CRPD implementation and their Implications for PWD in India Today***

Notwithstanding the fact that over a decade has passed since India’s ratification of the CRPD, the current analysis reveals widespread civil society concern over ongoing implementation failings and rights violations spanning the breadth of policy areas. The violations receiving most attention were in relation to education (accounting for almost a third of quasi-sentences, 31.5%); followed by law (21%), intersectionality (14%) and employment (12.9%).

The present study’s findings on education concur with recent work by Kumar and Agrawal (2019, p. 228) who note, ‘disability and particularly learning disability exclude a sizeable population of children out of school, increase dropout and [present] a challenge for universalization of education and development of any society ...’ Notably, the present study also reinforces recent work showing how PWDs’ exclusion is particularly pronounced in rural areas (Janardhana et al., 2015). The manifold failings in education are particularly troubling because, as the literature on generativity – or a concern for establishing and guiding the next generation (Erikson, 1950) highlights, cultural norms, attitudes and notions of prejudice are passed from one generation to the next (see for example Chaney, 2011). The exclusion of significant proportions of

**Table 3.** Medical model framing in the state discourse to the third cycle UPR.

Frame	Discourse – Example
Care	‘India has also put in place a number of schemes aimed at ... assistance, shelter, and overall care’ (para 136).
Protection	‘India committed to ensuring better protection for persons with disabilities’ (para 137).
Exceptionality/exclusion/need	‘India recognizes the need to take special measures to ensure that persons with disabilities enjoy the full range of human rights’ (para 137). ‘Recognizing the need for measures targeted at extending the benefit of developmental gains to persons with disabilities’ [rather than mainstreaming developmental gains – the emphasis here is on extension into an ‘other’ category of citizens].
Assistance (rather than empowerment)	[We will] ‘Provide legal aid and other assistance to mentally ill and mentally disabled persons in their interface with the legal system’ (para 47).
Vulnerability	‘Since persons employed in the unorganized sector are most vulnerable to destitution in the absence of social security ... assistance to ... persons with Disabilities’ (para 72).
Healthcare	‘Health ... The Act increases the number of recognized disabilities from 7 to 21, including disability due to ... thalassemia, haemophilia, muscular dystrophy, learning disabilities and Parkinson’s’ (para 139).

successive generations of PWD from formal education reinforces such discrimination and marginalization.

In the case of CSOs' highlighting rights violations in law and the administration of justice, particular attention centred on shortcomings in the legal code and failings in DWPs' access to justice. Such findings also resonate with recent studies. For example, referring to The Rights of Persons with Disabilities Act (2016), Chennapragada and Jain (2020, p. 191) observe that,

Since 2016, multiple complaints have been raised by India's disability rights community about the lack of implementation of the Act across India's states. The majority of Indian states are yet to adopt the central law and draft guidelines for state agencies and offices to implement the provisions of the new law.

In a similar vein, new research on India's Mental Healthcare Act (2017) that is designed to grant a legally binding right to mental healthcare to 1.3 billion people, highlights shortcomings in the drafting of the new statute and gaps in the protections it offers: 'Mental health services in India are substantially under-resourced ... the Act applies 'during delivery of mental healthcare and services' and not between episodes of care, when many violations of rights occur such as neglect, homelessness, imprisonment and social exclusion' (Duffy & Kelly, 2019, p. 60; see also Chadda, 2020). Moreover, extant work reveals how shortcomings in access to the justice system are part of a wider pattern of PWDs' exclusion from public services (Johnstone et al., 2019; Mathias et al., 2018).

This study's finding on intersectionality also resonates with recent research. For example, whilst Haq et al. (2020) highlight that much further work needs to be done to tackle intersectional inequalities, Dawn's (2014, p. 1768) research shows how,

The plight of women with disabilities is very depressing as they face a triple handicap and discrimination due to their disability, besides the gender issues. Violence against women with disabilities can range from neglect to physical abuse to denying them even the traditional roles of marriage and childbearing.

In terms of employment, the present findings resonate with recent studies, notably on the widespread patterns of exclusion and discrimination facing PWD in the workplace (Kundu et al., 2018); and crucially how this leads to multi-dimensional poverty (Pinilla-Roncancio et al., 2020).

Overall, this study reveals the oppression and suffering that ongoing rights violations bring to PWD and their families. The CSO discourse contains powerful accounts of rights-denial; discrimination; exploitation, violence and abuse. In the face of this, CSOs advocate immediate government action to move away from the dominant Medical Model of Disability that continues to shape much of public policy-making and, to instead, embrace the Social Model of Disability and uphold PWDs' rights to 'participation', 'access', and 'independence/(de-)institutionalization'.

The current analysis also reveals a series of classic policy-making pathologies underpinning contemporary rights denial. These include a *lack of political will* to act and address earlier Second Cycle UPR recommendations made in 2012; *inadequate resources* – meaning that government policy interventions and services are not equal to the task in hand; *implementation gaps* – where policies for PWD are adopted but

**Table 4.** Examples of key government public policy-making pathologies identified in CSOs' third cycle discourse.

Policy-Making Pathology	Examples from CSO/ UN Discourse
Lack of political will	'Despite accepting recommendations during the second cycle to Ensure better protection for persons with disabilities and the elderly, persons with disabilities remain particularly at risk of discrimination and violence. Many are locked up in overcrowded and unsanitary state mental hospitals and residential institutions, without following existing legal procedures that allow them to challenge such institutionalization, in part due to stigma and the absence of adequate community-based support and mental health services'. <sup>a</sup>
Inadequate resources	'While several housing schemes contain provisions for persons with disabilities, including preferential allotment, they are not sufficient and implementation is weak'. <sup>b</sup>
Implementation gaps	'On rights of women, children, and persons with disabilities, India should: oversee the implementation of laws dealing with sexual violence against women and children, including failures in police accountability'. <sup>c</sup>
Weak regulation, monitoring and enforcement	'the government has yet to put in place a systematic monitoring mechanism to ensure that state governments—tasked with implementing these laws—work cohesively with the federal government to adequately budget for their implementation, including through capacity building ... Women and girls with disabilities in particular continue to face barriers to accessing justice'. <sup>d</sup>
Inadequate data gathering on PWD	'Government should 'Comply with Article 31 – UNCRPD, by establishing data collection methods and systems in order to gather accurate statistics of persons with disabilities'. <sup>e</sup>
'Top-down' government – limited engagement with exogenous interests	'There is no due representation of ... persons with disability in these Committees. The inherent conflict of interests involved when the implementing agencies themselves become the monitoring bodies should also not be lost sight of. Considering the already existing responsibilities and commitments of ex-officio members, it might be a difficult task for them to effectively involve in monitoring on a regular basis'. <sup>f</sup>

<sup>a</sup>Human Rights Watch (2016, p. 1).<sup>b</sup>Housing and Land Rights Network India (2016, p. 6).<sup>c</sup>Human Rights Watch (2016, p. 2).<sup>d</sup>Action Aid Association (2016, p. 12).<sup>e</sup>Action Aid Association (2016, p. 14).<sup>f</sup>The Centre for Child and the Law, National Law School of India University, Bangalore (2017).

are not followed through; *weak regulation, monitoring and enforcement* – in other words a lack of accountability in relation to policy delivery; *inadequate data gathering* on PWD; '*Top-down*' government – and limited engagement with exogenous interests; a failure to adopt *strategic leadership* to secure CRPD implementation; and, the absence of a *participatory approach* to public policy-making based on PWDs' input at all stages (Table 4).

Overall, this study shows how four factors emerge from the civil society UPR discourse and confirm the existence of institutional ableism in the Indian polity: 1. the breadth of rights violations spanning policy areas; 2. The framing of the civil society discourse and the way it highlights *systemic* rights-denial, discrimination, exploitation, violence and abuse; 3. poor levels of descriptive representation of PWD (in parliament, state assemblies and public decision-making forums); and 4. A series of policy-making pathologies (*inter alia*, lack of political will; inadequate resources; weak regulation, monitoring and enforcement).

## Conclusion

This study makes an original contribution by presenting a systematic analysis of the situated knowledge of civil society organizations founded on their day-to-day experience of representing and working with people with disabilities. This reveals how a broad range of policy pathologies are arresting progress in advancing the rights of PWD in today's India. In particular, CSOs point to how institutional ableism is hampering effective CRPD implementation. This underlines the need for further transformation of social and governance practices, including strengthening the capacity of civil society organizations representing PWDs, and an end to ongoing government suppression of civil society (Chaney, 2020; Chaney & Sahoo, 2021; Humble & Mani, 2018). It also signals the need for stronger international monitoring and enforcement of CRPD rights, as well as a 'step-change' improvement in equalities data-gathering.

As the foregoing suggests, there is not a single panacea to address the current malaise. However, there is a policy tool with the potential to improve the situation, namely human rights impact assessments (HRIAs). Internationally used in relation to equalities legislation (equalities impact assessments or EIAs), and part of the broader family of social impact assessments (Esteves et al., 2012), HRIAs are a holistic, proactive policy tool designed to predict the human rights impact of public policy. Their strength is that they consider all stages of policy-making, making use of baseline data, and they give attention to process, allocation of resources, likely impacts and necessary mitigating factors. In addition, they are predicated on the participation of civil society. HRIAs are not a one-off action, but incorporate the need for ongoing monitoring and evaluation (Andreassen & Sano, 2007). Accordingly, placing a legal duty on public bodies requiring them to use HRIAs would be a useful advance in upholding the CRPD in public policy and services.

A final area where change is needed is social attitudes to disability. This is a major issue owing to the intergenerational transmission of prejudice and discriminatory attitudes towards disabled people. Equal access to the education system and increasing the number of disabled people in decision-making forums in public life will help to address this issue. Whether future, India-focused research reports on CRPD implementation success or policy failure, will to a large degree, depend upon the extent to which these factors are addressed and government responds to the issues identified in the analysis presented here.

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