

“Our Blood Itself Is Disabled!”

Haemoglobinopathy, Certificate Anxiety, and Contested Constitutionalism in Disability Legislation in India

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Abstract

On 28 December 2016, the Government of India passed a national disability act which for the first time recognised genetic blood disorders—thalassemia, sickle cell disease, and haemophilia—as disabilities, entitling affected individuals to affirmative action. While it was welcomed by patient communities, this policy decision also sowed seeds of collective anxieties regarding the assessment of the required degree of disability in affected individuals. Thirteen months later, a set of national guidelines were published that dictated the procedures for determining whether a patient meets this ‘benchmark disability’ standard, thus materialising the collective anxieties of blood disorder patient communities. Utilising ‘patchwork ethnography’ as a methodology, in this article I focus on haemoglobinopathy (thalassemia and sickle cell disease) patient communities in India to investigate the ‘certificate anxieties’ that stem from the difficulties of certifying disability percentage for those with genetic blood disorders. These anxieties arise from the tensions between a (bio)constitutional reordering of disability categories and the contestations of these categories, which are rooted in articulations of citizenship rights. I argue that such contested constitutionalisms give rise to productive tensions in State–(disabled) citizen relations that have the potential to realign institutions with citizens’ accounts of social justice.

Keywords

Genetic blood disorders, Bioconstitutionalism, Biocitizenship, Disability certification, Affirmative action.

Introduction

The late Sampat Tukaram Ramteke has an enduring legacy among blood disorder patient advocacy groups in India. ‘You must surely know about Sampat Ramteke *ji*’s¹ pathbreaking contribution to our cause?’, a sickle cell patient advocate asked me enthusiastically during a conversation. Sickle cell disease and thalassemia are recessively inherited blood disorders that arise due to incorrectly formed haemoglobin molecules as a result of genetic mutations (Iyer et al. 2015). These rare genetic conditions that result in serious medical complications—such as reduced haemoglobin levels and need for frequent blood transfusions—are collectively termed ‘haemoglobinopathies’ in the biomedical literature. It was owing to Sampat Ramteke’s advocacy that sickle cell disease, along with thalassemia and haemophilia, was included as a disability in India’s most recent national disability legislation, the Rights of Persons with Disabilities Act 2016 (hereafter, RPWD Act 2016). For his contributions, Sampat Ramteke was posthumously awarded the Padma Shri award for social work, a prestigious Indian civilian honour.² Ramteke began his activism after his son was diagnosed with sickle cell disease at an early age. An engineer by training, Ramteke belonged to a historically and socioeconomically marginalised *Dalit*³ community in the state of Maharashtra, in western India.

An episode on his activism for sickle cell disease as part of a documentary series on notable social workers is perhaps the most intimate introduction to Ramteke’s reflections on life, care work, and patient advocacy.⁴ Produced in 2014, the documentary series, titled ‘*Main zindagi ka saath nibhata chala gaya*’ (‘I kept going along with life’), takes its name from a classic Hindi song that poetically extols the virtues of tenacity and perseverance in the face of the myriad challenges of life—meant to represent Ramteke’s struggle in the aftermath of his son’s diagnosis. The episode opens with scenes of Ramteke engaged in everyday advocacy work: working on a computer in a nondescript office; reclining on a bed at home diligently studying the ‘elements of medical genetics’; taking notes on an office desk surrounded by stacks of files containing documents weathered by time; assisting patients and interacting with physicians in clinics. These opening scenes of Ramteke’s life, meticulously and intentionally sequenced, depict the uneventful everyday work of patient advocacy that is involved in becoming educated and educating others about ‘invisible’ health conditions (Ciribassi and Patil 2016) that affect millions across the world. As the film progresses, Ramteke narrates the

1 In Hindi, *ji* is a reverential suffix most often used after a person’s name to connote respect.

2 See https://padmaawards.gov.in/padma_home.aspx.

3 *Dalits* are the former ‘untouchables’, who are pejoratively characterised as ‘lower caste’. For an understanding of caste and *Dalit* experiences, see Ramnarayan and Satyanarayan (2016).

4 See <https://www.youtube.com/watch?v=LqojODck52I>.

challenges he faced, owing to his family’s socioeconomic status, in acquiring an education and an engineering degree. He goes on to describe how his life improved once he became an engineer and started his family: ‘Life was happy!’ But this happiness was soon marred by his son’s progressively aggravating sickle cell disease. The most poignant moment in the narration of the film comes after around 20 minutes, when a voiceover expresses Ramteke’s anxieties about living with sickle cell disease: ‘It is beyond comprehension why our health sector is so indifferent towards sickle cell disease.’ It is this anxiety that led Ramteke to form the first patient advocacy organisation in Maharashtra for sickle cell disease, the Sickle Cell Society of India, which was eventually able to effect policy changes for the rights of sickle cell patients in the country.

In December 2019, three years after blood disorders were included in the RPWD Act 2016, I was aboard a local train for a preliminary field visit in Chhattisgarh, an insurgency-affected state in central India with a high prevalence of sickle cell disease (Panigrahi, Patra, and Khodiar 2015; Patra et al. 2015). I was travelling from Chhattisgarh’s capital city of Raipur to the remote city of Bilaspur to meet with another disability rights patient advocate for sickle cell disease, Reetesh Naik. In his late thirties, Naik is homozygous for the sickle cell gene and suffers from serious manifestations of the condition, including episodes of pain (commonly known as ‘pain crises’), anaemia, and chronic fatigue. The founder of the Sickle Cell Welfare Society in Chhattisgarh, Naik reflected on the invisibility of sickle cell disease during our initial meeting, telling me: ‘Those who suffer from sickle cell disease are more disabled than the visibly disabled’, concluding that ‘*Humara toh blood hi disabled hain!*’ (‘Our blood itself is disabled!’).

Sitting in the basement restaurant of one of the few hotels in Bilaspur, where I was staying, Naik showed me the brochures, leaflets, and pamphlets that his organisation had published and disseminated to raise awareness among the public and policymakers about sickle cell disease. However, the document that he emphasised the most was a copy of the RPWD Act 2016. Pointing to the clause in the Act that states the inclusion of genetic blood disorders, Naik described to me the significance of the affirmative action that the Act guarantees for people with disabilities in India, and the paramount importance of haemoglobinopathy sufferers having been included in this legislation. Nonetheless, Naik was not completely satisfied with the legislation as it excluded the three blood disorders from affirmative action in relation to guaranteed employment. For all disabilities included in the legislation, in order to benefit from these constitutional guarantees it must be demonstrated that individuals’ percentage of disability is at 40 per cent or more. This figure is an existing medico-legal epistemic construction and a status that the RPWD Act 2016 now terms ‘benchmark disability’. This policy directive has since come to be ardently contested by haemoglobinopathy patient communities. They

feel that the new requirement, while formally guaranteeing access to affirmative action for a minority of blood disorder patients who are able to satisfy the ‘benchmark disability’ criteria, is nevertheless misinformed and misleading, resulting in renewed anxieties about disability certification that I call ‘certificate anxieties’.

In this article, I investigate certificate anxieties regarding the quantification of disability due to haemoglobinopathies in India, and the contested constitutionalisms that they engender. I use ethnographic vignettes derived from ‘ethnography-at-a-distance’—necessitated in the wake of the COVID-19 pandemic—to discuss certificate anxieties as subjective instances that illuminate the ‘frictions’ (Tsing 2005) that are generated when universalising biomedical constructs such as ‘percentage of disability’ meet with the local particularities of expert assessments of extent of disability. Anthropologist Anna Tsing describes ‘frictions’ as discomfitures and divergences that arise within synergistic and collaborative action to achieve common social goals. I suggest that frictions around haemoglobinopathies are produced when ‘bio-constitutionalism’ (Jasanoff 2011a)—that is, the institutionalisation of novel social orders around life and life processes, such as new disability categories constructed at the intersection of policy and medicine—intersects with an assertion of ‘biological citizenship’. Anthropologist Adriana Petryna (2002) describes ‘biological citizenship’ as the constitutional rights of citizens that are rooted in collective biological conditions. Far from illuminating antagonisms between established theoretical frameworks which are critical for understanding complex sociotechnical realities, this research article instead offers insight into the productive tensions that emanate from the frictions between bioconstitutionalism and biological citizenship in India that determine how biomedicine, the State, and citizens interact (Hurlbut et al. 2020) on issues around disability. In the remainder of this article, I demonstrate that the contestation of the bioconstitutional reframing of genetic blood disorders as subject to the standard of ‘benchmark disability’ stems from the biological citizenship asserted by patient communities demanding constitutional recognition of their disabled embodiments. The methodology employed utilises ‘patchwork ethnography’ (Durban 2021; Gibson 2019) undertaken between December 2019 and May 2021, as well as documentary analysis to investigate recalibrations in the multifarious relationships between biomedicine, the State, and citizens (Brás 2018) which are rooted in everyday experiences of affliction in India (Das 2015; Banerjee 2020). Patchwork ethnography emphasises the epistemic value of multi-modal ethnographic immersions, both as an inclusive methodological strategy for differently-abled and gendered social researchers (Günel, Varma, and Watanabe 2020) and as a response to restrictions on in-person research, including during the COVID-19 pandemic. The ethnographic vignettes and insights I present in this article are thus derived from the following modes of immersion: participant

observation in online webinars jointly organised by patient advocacy groups and biomedical experts; participant observation in online group chats utilising the online communication platform WhatsApp; in-depth interviews and conversations with sickle cell patient advocates in Chhattisgarh and Maharashtra utilising WhatsApp and the online conference platform Zoom; and analysis of media articles about haemoglobinopathy patient communities. The documentary analysis comprises a critical reading of disability policy documents as well as judgements from haemoglobinopathy legal disputes which invoke the RPWD Act 2016. Taken together, these discourses chart the everyday negotiations between constitutionalism and citizenship in relation to disability due to blood disorders in India.

I begin with a brief discussion on the changing definitions of disability in India, their impact on policy formulations and disability jurisprudence, and the citizenship rights that have come to be asserted as a result of these shifts. In the section that follows, I discuss in detail the certificate anxieties that arise when proving ‘benchmark disability’ for haemoglobinopathies. These anxieties have implications, as I go on to show, for assertions of a biological citizenship that is centred on reparations for chronic disability due to genetic blood disorders. I then investigate the epistemic basis of establishing ‘benchmark disability’ status, interpreting this as a bioconstitutional reframing of disability ontologies that simultaneously recalibrates State–(disabled) citizen relations in India. The article concludes with a discussion of the productive tensions generated through the frictions between expert assessments of experiences of blood disorders and intimate understandings of disability held by haemoglobinopathy patient communities in India. I argue that these frictions, as embodied by patients in the form of certificate anxieties, give rise to contested constitutionalisms. These contestations in turn provide avenues for broader understandings of ways to align the State in relation to its citizens, and vice versa, in a manner that enables national institutions to ensure social justice.

Constituting disability in India: Policy, jurisprudence, and citizenship rights

In India, the notion of ‘disability’ has undergone radical transformation, initially from disability as a signifier of racial and social inferiority (Nair 2017; Grech 2015) to a religious notion of disability (Gupta 2011)—which within the Hindu cosmology is often associated with the consequences of actions committed in past lives. This was succeeded by a medical discourse on the management of disability in the post-liberalisation period of the 1990s (Jha 2016) and in the last decade the focus has increasingly been on the social situation of Indian disability in relation to gender, caste, and class (Buckingham 2011).

The first disability legislation to be constituted in India was the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 (hereafter, the PWD Act 1995): the first law to directly address issues pertaining to the disabled population of India, though it did not adequately account for the social realities of India’s differently abled. Rather, legislative and judicial discourses following the enactment of the PWD Act 1995 were largely focused on the medicalisation (Conrad 2007) of disability, seeking to determine the degree of ‘difference’ between able-bodied and differently-abled citizens in order to ensure equality of opportunities and freedom from discrimination (Addlakha and Mandal 2009). Despite such a clinical approach to disability rights, an understanding of disability rooted in immediate circumstances has nevertheless been invoked by Indian courts in disputes in legal proceedings regarding technical determinations and definitions (Addlakha and Mandal 2009, 64–66), indicating a cognisance of the social contexts of disability in Indian jurisprudence. In Indian courts, therefore, disability has a history of being treated as an ‘evolving concept’ even when it has been equated with ‘illness’ through a medicalising legal discourse (Mandal 2010) prior to the enactment of the RPWD Act 2016. Nevertheless, such reductive medico-legal interpretations have been consistently challenged by the disability rights movement that took shape in India at the beginning of the 1980s (Mehrotra 2011).

The disability rights movement of the 1980s advocated for a social model of disability to ensure protection from discrimination as well as educational and employment opportunities for all people with disabilities in India (Kannabirān 2012; Reddy 2011). It was this social movement that paved the way for a rights-based discourse on differently-abled embodiments (Breckenridge 2001) in India which eventually led to the formulation of the RPWD Act 2016. The global adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006 (hereafter, UN CRPD 2006) had a direct impact on disability policy formulations in India (Kothari 2010), contributing to the institutional focus in the RPWD Act 2016 on the local contexts within which differently-abled embodiments are experienced in India (Hernandez 2008).

The UN CRPD 2006 marked an important moment in global deliberations on disability, as it ratified internationally the shift from a medical model to the more inclusive social model of disability. Renowned Indian activists like the late Javed Abidi leveraged this shift to lead a cross-disability movement in India that emphasised the importance of the social approach for the protection of the basic human rights of all differently-abled peoples (Abidi and Sharma 2013). The significance of the social model in Indian disability legislation was not only perceived as giving a voice to India’s ‘invisible minority’ in policymaking (Abidi and Sharma 2013, 11), but it also reshaped social attitudes towards individuals with

disabilities in the country (Dias 2013). The disability advocacy movement therefore served as a precedent to contemporary articulations of biological citizenship based on disabled embodiments in India.

Consider for example an excerpt from an appeal made by a haemophilia patient advocate on 4 March 2013 addressing the Department of Disability Affairs through the question and answer segment of the proceedings of the Indian Parliament.⁵ Blood disorders were not originally included in the draft Rights of Persons with Disabilities Bill in 2012 (which was subsequently enacted as the RPWD Act 2016). This parliamentary appeal petitioned the State for the inclusion of thalassemia and haemophilia in it. The appeal reads:

Hemophilia Federation India is a self-help organization working for the welfare of people with Hemophilia. This organization has been trying hard for the last 29 years for inclusion of Hemophilia particularly in the Persons with Disabilities Bill. But without any effect. As per survey it is observed that the numbers of Hemophilia affected patients are growing everyday causing threat.

I demand that the Government should seriously take care of the remaining two life threatening diseases and immediately include in the category of benchmark disability.

This testimonial of 29 years of patient advocacy to achieve recognition for haemophilia—a disease that the patient advocate describes as ‘life threatening’—as a disability within the Indian legislative system is an unmistakable assertion of citizenship rights centred on chronic biological suffering (Kleinman 1988). Furthermore, the advocate’s broader ‘demand’ to include haemophilia and thalassemia in the disability legislation is a definitive claim of a constitutional entitlement that is rooted in genetic embodiment. The subsequent decision by the Government of India to include blood disorders in the RPWD Act 2016 can therefore be interpreted as a constitutional moment (Jasanoff 2011b) in the history of disability legislation in India. Jasanoff describes constitutional moments as moments of political change in democratic societies wherein ‘the relationship between experts, who underwrite almost all contemporary state action, and citizens, who are collectively subject to the decisions of states’ (idem, 623–24) is renegotiated. I read the recognition of blood disorders as disabilities in response to demands by patient advocacy groups as a constitutional moment that reinvents the relationship between the Indian State and citizens affected by blood disorders,

5 The question and answer segment is open for participation by all Indian citizens who wish to address their concerns to the State. See the 4 March 2013 appeal: <https://eparlib.nic.in/handle/123456789/742954>.

based on a guarantee of the fundamental right to life and dignity as enshrined in Article 21 (‘Protection of life and personal liberty’) of the Indian constitution.⁶

A legal dispute filed against the Medical Council of India by Sruchi Rathore, a 19-year-old thalassemia-affected aspirant for medical school, demonstrates how the inclusion of blood disorders in the RPWD Act 2016 has shaped both judicial discourses as well as assertions of citizenship rights around disability embodiments.⁷ This exemplary case was heard in the Supreme Court of India on 18 August 2017, and also became a precedent for a later highly publicised case on affirmative action for equal educational opportunities for students with haemoglobinopathies in India (Bhatnagar 2017). In *Sruchi Rathore vs. Union of India*, the petitioner was at the time seeking admission to a medical college in Chhattisgarh and was denied entry despite the affirmative action clause of the RPWD Act 2016 for people assessed to have ‘benchmark disability’, as she had been. Having determined that the petitioner did indeed satisfy the criteria for ‘benchmark disability’ due to a blood disorder, the Supreme Court directed the Medical Council of India to ‘admit the petitioner in the requisite course’. The reasoning of the apex court in passing this judgement in favour of the petitioner affected by a haemoglobinopathy represents a paradigm shift in disability jurisprudence in India. The following excerpt from the verdict aptly inscribes this institutional shift:

The said statutory command, needless to say, has to be followed in letter and spirit. We are disposed to think so because the 2016 (RPWD) Act, as we perceive, is a legislation of great welfare measures and it is the duty of everyone to see that the provisions are carried out with quite promptitude.

The court describes the RPWD Act 2016 as embodying ‘great welfare measures’ directed at differently-abled citizens, and that it is the ‘duty of everyone’ to implement the legislation ‘in letter and spirit’. The Supreme Court interprets the disability legislation as executing welfare measures through affirmative action, guaranteeing equal opportunities in education and employment, and therefore as a policy that recognises and accounts for the social dimensions of being differently abled in India. That according to the Supreme Court of India the upholding of this legislation in totality is an obligation for ‘everyone’—meaning all citizens of India—is representative of the impact of the RPWD Act 2016 on disability jurisprudence in India.

6 Article 21 of The Constitution of India, ‘Protection of life and personal liberty’. See <https://legislative.gov.in/sites/default/files/COI...pdf>.

7 *Sruchi Rathore vs Union Of India*, 18 August 2017. For the text of the judgement, see <https://indiankanoon.org/doc/102595185/>.

Nevertheless, it must also be noted here that the Supreme Court’s judgement in the case, although in favour of the petitioner, has continued to rely on a biomedical determination of the degree of disability in an affected person, thus revealing a persistent biomedicalisation (Moyer and Nguyen 2016) of the legal discourse on disability in India. ‘Welfare measures’ as institutionalised sociopolitical technologies of equity have doubtless been made implementable through this medico-legal category which is constituted at the intersections of biomedicine and legislature. The caveat in the constitution of ‘benchmark disability’, however, is that it serves to exclude from these very sociopolitical technologies of equity those disabled individuals who are unable to certify their disability as meeting this requirement. The concern among haemoglobinopathy patient communities regarding misinformed disability policies stems from these very caveats. It is such exclusions that generate tensions between the certification of blood disorders as fulfilling the criteria for ‘benchmark disability’ status on one hand, and the intimate knowledges of disability held by haemoglobinopathy patient communities in India on the other. In the following section, I discuss the certificate anxieties of haemoglobinopathy communities with a view towards highlighting some key tensions around this certification.

Certificate anxieties: Contested constitutionalisms and productive tensions

In 2018, the Department of Empowerment of Persons with Disabilities released a gazette notification enumerating a set of national guidelines on disability certification (hereafter, the 2018 disability certification guidelines),⁸ which specified the procedures for the evaluation of all disabilities included in the RPWD Act 2016. The number of legally recognised disabilities had been expanded from seven in the preceding PWD Act 1995 to 21 in the RPWD Act 2016, among which were blood disorders. Less than three weeks after the 2018 disability certification guidelines were published, an article in the widely-read Indian newspaper *The Hindu*, explored the worry among thalasseemics in India regarding the certification of thalassemia:

The thalassemia community was relieved when the blood disorder was recognised as a disability in 2016, but the recent gazette notification that has given guidelines for certification has left them very worried. The guidelines say disability certificate can be given only on the basis of associated conditions in the patients, such as the number of blood transfusions, signs of bone marrow hyperplasia, and osteoporosis. They say it’s incorrect to use percentage benchmark for blood disorders like thalassemia. A thalassemia major person

8 See Government of India, Ministry of Social Justice and Empowerment (2018).

who is dependent on blood transfusions for life is 100% disabled as it is a progressing, genetic disorder. This is unlike a visually disabled person, who can be certified as 50% visual disabled if one eye has an issue (Yasmeen 2018).

The excerpt captures the essence of the certificate anxieties of the thalassemia community in India, expressed as a collective discontent regarding the flattening of all disability experiences (Jeffery and Singal 2008) through the standard of ‘benchmark disability’. Indeed, experiences of disability due to blood disorders are markedly different from experiences of, for instance, disability due to visual impairment. These certificate anxieties are therefore generated as a result of the ‘frictions’ between a universalising, standardised process of disability certification for implementing affirmative action and the pragmatic challenges for blood disorder sufferers of proving ‘benchmark disability’ to access these affirmative actions. As is demonstrated by scholarship in science and technology studies (STS) (Merz 2021; Quark 2019), processes of standardisation have an inherent tendency to erase embodiments and particularities in favour of commensurabilities. Similarly, ‘benchmark disability’ as a policy device for standardising disability evaluations erases the chronicity of disabilities specific to haemoglobinopathies.

The anxieties among haemoglobinopathy patient communities generated in response to such flattening of disability experiences were further aggravated by the initial stipulation in the 2018 disability certification guidelines to annually review disability certificates granted to individuals with blood disorders; a guideline that was later modified in the face of resulting contestations by patient communities. Such a statutory guideline stemmed from the perception among policymakers that blood disorders are ‘progressive’ in nature. Here, the term ‘progressive’ in relation to stages of haemoglobinopathies appears to represent an ‘interpretive flexibility’ (Lakoff 2004): that is, it is interpreted differently by patients and policymakers. Whereas ‘progressive’ is interpreted for policymaking purposes as having some ambiguity, within the lifeworlds of haemoglobinopathy patients ‘progressive’ means ‘permanence’ and, in some cases, it flags an ‘inevitability’ of disability. It is this permanence of suffering among haemoglobinopathy patients that is not recognised in India’s current disability legislation, and which exists in tension with the temporal interpretation of the severity of disability due to blood disorders.

Frictions therefore exist between policy framings of haemoglobinopathies as disability and the situated experiences of impairment (Bharadwaj 2013) due to these blood disorders. In other words, frictions arise between the bioconstituting of blood disorders as ‘progressive’ disability, subject to continuous expert evaluations against the standard of ‘benchmark disability’, and citizenship claims among haemoglobinopathy communities demanding ‘permanent’ disability status.

These frictions give rise to contested constitutionalisms that are thus rooted in collective anxieties among haemoglobinopathy communities about producing disability certificates in order to access affirmative action. The resulting contestations raise a pertinent question about policymaking for haemoglobinopathies: How can the degree of disability be measured when the very blood flowing in a patient’s veins causes chronic injury?

In the newspaper article in *The Hindu* above, the thalassemia community’s claim that a thalassaemic individual is ‘100% disabled’ also resonates with the emphatic statement that Naik, the disability rights patient advocate from Chhattisgarh, made to me regarding sickle cell disease: ‘Our blood itself is disabled!’ I read this statement as a profound claim of chronic biological injury. Individuals with genetic blood disorders have to manage their condition throughout their lives; often this also means coping with socioeconomic impairments like loss of educational, employment, and kinship (most notably, conjugal) opportunities. Biological injury due to disabled blood therefore seeps into the subjective realities of differently-abled individuals.

In my continued interactions with Naik since December 2019, time and again I have found myself being drawn back to the matter of the specific exclusion of blood disorder sufferers from affirmative action for employment opportunities guaranteed in the RPWD Act 2016. In August 2018, eight months after the 2018 disability certification guidelines had been published, Naik and representatives of four other disability rights associations wrote a letter to the Prime Minister of India demanding affirmative action to guarantee equal opportunities of employment for the five disability groups⁹ excluded from the affirmative action clause for employment guarantee in the RPWD Act 2016 (Chhetri 2018). This collective of disability rights associations claimed that exclusion from employment opportunities is a violation of the ‘basic spirit’ of the UN CRPD 2006. The claim takes me back to when I first met Naik, a year on from the letter, and was struck by the emphasis in his patient advocacy on the need for policy change to ensure employment opportunities for sickle cell patients. At the time I wondered why Naik focused so exclusively on the affirmative action clause in disability legislation for employment opportunities. In a later conversation, this time by a WhatsApp voice call in May 2021, in the middle of the deadly second wave of the COVID-19 pandemic in India, I asked Naik about his health and how he was coping in the midst of a pandemic. He replied to my mundane question in a pensive manner, ‘Each day is new, each day brings a new challenge. For sickle cell patients, the focus is always on survival.’ Indeed, survival has become a fight for Naik, who was recently diagnosed with tongue cancer and had undergone surgery that has now left him with an additional mild speech

9 The five disabilities excluded from affirmative action for employment guarantee are sickle cell disease, haemophilia, thalassemia, Parkinson’s disease, and multiple sclerosis.

impairment. Naik’s sombre ruminations about his biological condition helped me understand his certificate anxiety very poignantly. When each day is a new struggle that brings unanticipated challenges, having access to guaranteed employment often becomes a matter of life or death for individuals with chronic disabilities. Sickle cell disease not being recognised as a permanent disability has meant that its sufferers repeatedly face unemployment, and hence crushing financial insecurities. Such vulnerability is, I argue, against the ‘basic spirit’ of the social model of disability.

The focus on the social model of disability within disability discourses in India has fostered the formation of various patient advocacy groups. These groups have continuously highlighted the socioeconomic contingencies of disabled communities in India. It has been shown in the United States that online communities are becoming increasingly significant as emerging social formations that propel discourses on disability activism through technology (Thompson 2019). This also holds true for disability activism in India, particularly with the ubiquity of virtual organising in the aftermath of the COVID-19 pandemic. Within the larger online sickle cell patient community, of which I am part, there is an engaging critique of the 2018 disability certification guidelines in relation to affirmative action. Although the issue of certification is just one among the myriad challenges that the sickle cell patient community faces, concerns regarding certification surface from time to time in online fora, particularly when new policy changes are effected or when a member seeks to claim available disability benefits. Precisely in such a moment of resurfacing, I came in contact with Sumukhi S. (a pseudonym), another sickle cell patient advocate who is also a member of this online patient group. Sumukhi reached out to me via WhatsApp voice call early in 2021 when she learnt about my academic engagement with disability legislation in India. She was particularly interested in discussing with me the caveats in the current disability policies pertaining to haemoglobinopathies. Sumukhi hails from a middle-class family and has access to the necessary and available means for effectively managing her condition. Despite her agential social status, she too expressed her certificate anxieties in relation to the ‘benchmark disability’ criteria for blood disorders. During a voice call, Sumukhi questioned the expert evaluation of ‘benchmark disability’ for blood disorders:

The issue is with the reasonings embedded in these legislations. There are many loopholes in the criteria for providing disability certification. Why is there a need to annually review disability certification for blood disorders? I want to investigate these shortcomings in the disability laws so that I can point them out.

Being a highly educated sickle cell advocate, Sumukhi has a deep understanding of disability jurisprudence and policymaking. Her certificate anxieties regarding ‘benchmark disability’ therefore originate in the perceived arbitrariness of the guidelines for disability certification for blood disorders. Sumukhi’s determination to investigate how the criteria for certification were arrived at in the current disability legislation is ultimately directed towards understanding how the existing legislative framework can be amended to address the real problems of sickle cell individuals in India. In her narration of her own certificate anxieties regarding the arbitrariness of policymaking, Sumukhi asserts a citizenship right that aims to critically analyse the reasonings employed by experts in determining guidelines that have a direct impact on the lifeworlds of blood disorder patients. Sumukhi seeks to investigate the gaps in these expert framings through a critical lens that is informed by patient perspectives. In other words, she seeks an avenue through which to recalibrate the bioconstitutional reframings of the rights of citizens with haemoglobinopathies in India as determined by the current disability legislation. In so doing, Sumukhi contests the bioconstitutional reordering between the State and haemoglobinopathy patient-citizen relationship through the standard of ‘benchmark disability’, offering instead a vision of this reordering that is reflexive in response to the ground realities of living with blood disorders in India. These contestations therefore illuminate how lived experiences of rare genetic afflictions, and patient group organising around biological injury, have the capacity to unsettle the arbitrations embedded in expert framings of citizenship rights.

Another sickle cell patient advocate, Gautam Dongre, also contested these expert reorderings of the conditions of access to legal disability entitlements for India’s haemoglobinopathy patient communities. A friend of Ramteke’s, and hailing from the same state of Maharashtra, Dongre is also the Member Secretary of an alliance for sickle cell associations in India, the National Alliance for Sickle Cell Organizations (NASCO), also based in Maharashtra. Dongre has the sickle cell trait—that is, he has one copy of the sickle cell gene, and does not show serious symptoms of the disease. Two of his three children however, aged 10 and 16, are homozygous for the sickle cell gene and are affected by serious manifestations of the disease. In our first online conversation in early 2021, Dongre introduced himself to me as a ‘sickle cell care giver’. This term has come to be increasingly used by sickle cell carriers who do not suffer from the disease themselves but witness and struggle with their children’s suffering due to their homozygous condition. During a remote conversation, Dongre narrated to me his certificate anxieties about the current disability legislation and expressed his discontent with the policies ascribing a temporary status to disabilities arising due to blood disorders. Embedded in the temporary status is the arbitrary assumption that the seriousness of these disabilities arising from blood disorders is variable, and that

an affected person can effectively manage their disorder with the right treatment. Dongre, however, expresses his frustration at the resulting exclusions:

Many sickle cell patients belong to marginalised and ‘tribal’ communities who are socioeconomically disadvantaged. Often, they are unable to reach the corridors of our formal institutions to make their voices heard. Under these circumstances, the need to periodically renew their disability status adds to their everyday struggles. They simply cannot afford it. Determining the percentage of disability due to blood disorders has become a serious difficulty.

In his articulation, Dongre connects the ‘temporary status’ conferred upon these individuals to the difficulties faced by patients belonging to marginalised communities in obtaining disability certificates. His anxieties about the temporary status draws attention to those sickle cell-affected individuals who often fall through the cracks of formal institutions owing to their positionality. As Ruha Benjamin has argued, biological citizenship can only be asserted by those in relative positions of privilege and proximity to formal institutions (Benjamin 2013). Indeed, Dongre’s organisation NASCO is one of the many sickle cell organisations across the world that is supported by a pharmaceutical company (in NASCO’s case, by Novartis)—a corporate manoeuvre for creating new markets with patient advocates acting as vanguards, a phenomenon well described in the medical anthropology literature (Dumit 2012). Notwithstanding corporate involvement, Dongre’s narration of the challenges faced by these presumably distant subaltern ‘others’ (Rao 2009) in the articulations of his own certificate anxieties reflects a collective sense of entitlement to the State’s intended inclusive policies, regardless of pharmaceutical motives. Established patient advocacy groups therefore represent the mainstream narrative of organising around disability embodiments.

When the 2018 disability certification guidelines were passed, there was a sharp reaction among patient advocacy groups in India against the requirement for the annual renewal of disability certificates for blood disorder sufferers, as the accounts above illustrate. NASCO and Dongre were a part of this advocacy. As a consequence, the requirement was amended on 3 August 2021 through a statutory notification which now stipulates that the renewal of disability certificates for blood disorders needs to take place only every three years.¹⁰ These contestations resulting from certificate anxieties among haemoglobinopathy patient communities in India can be interpreted as collective reactions to moments of institutional arbitrariness (Gupta 2012) that are nevertheless held to account by citizenship claims about constitutional rights to life and liberty. Moreover, anxieties regarding certification are also anxieties regarding the flattening impact of standardisation. Certificate anxieties thus foster contested constitutionalisms that demonstrate how

10 For the text of the notification, see: <https://www.egazette.nic.in/WriteReadData/2021/228751.pdf>.

institutions and citizens come to frame and reframe one another. Whereas bioconstituting the certification of blood disorders through the standard of ‘benchmark disability’ has been framed by the State as a mechanism of inclusion, the same framing has been contested by haemoglobinopathy patient advocates in India who highlight the resulting exclusions. These institutionalised exclusions, as I discuss above, have real world implications for such affected individuals as are unable to prove ‘benchmark disability’, and consequently lose access to much-needed State-sanctioned aid, often critical for ameliorating their disabled condition. It is therefore pivotal that institutions realign in response to frictions and the resulting contested constitutionalisms in order to promote substantive justice imperative to a democratic polity, particularly in relation to disability rights. These contested constitutionalisms pave the way for a reflexive bioconstitutionalism in India’s legislative system.

Disabled blood: The problems of certifying ‘benchmark disabilities’ in India

The 2021 amendment of the disability certification guidelines exhibits a capacity for reflexivity embedded in India’s legislative institutions, allowing them to be responsive to citizens’ articulations of their own citizenship rights. In the preceding sections, I have suggested that the contested constitutionalisms that arise from certificate anxieties are an assertion of a form of biological citizenship that seeks to reconstitute (Smith 2016) disability ontologies through negotiations with state institutions. To further contextualise the importance of reflexive bioconstitutionalism, it is imperative to investigate how possibilities for epistemic exclusions come to be embedded in constitutional reorderings around life and life processes. Certification of ‘benchmark disability’ for blood disorders as medico-legal documentation (Neves 2020) enabling access to affirmative action represents ‘a repositioning of human bodies and selves in relation to the state’s legal, political, and moral apparatus’ (Jasanoff 2004, 4). In other words, it constitutes a bioconstitutional moment in which ‘the constitutional is articulated with the biomedical’ (Sunder Rajan 2011). In the RPWD Act 2016, a ‘person with benchmark disability’ is defined as ‘a person with not less than forty percent of a specified disability’. Such a percentage criterion for assessing the extent of disability in an individual has, as we have seen, also been utilised in previous disability legislation, i.e., in the PWD Act 1995. However, the mechanism of standardising disability caused by haemoglobinopathies through certifying ‘benchmark disability’ is an act of ‘making up’ (Hacking 1987) or reordering haemoglobinopathy ontologies. For policymaking in a country like India, with a large differently-abled demography, this nonetheless instrumentalises a biomedical conceptualisation of disability in order to realise the social goal of

substantive justice. This reordering represents a bioconstitutional moment in the history of India’s disability legislation.

Moreover, within the ambit of the 2018 disability certification guidelines, the procedures for ascertaining degree of disability (and so determining whether an individual has ‘benchmark disability’) for haemoglobinopathies, and all other included disabilities, rely upon specific value judgements. Although drawing upon existing norms¹¹ for arriving at a disability index, it must be noted that the existing norms are already shown to include subjective evaluations of disability (Maska, Anderson, and Michaud 2011), alluding to a mutual constitution of medical standards and embodied experience (Mol 2003). The two tabular illustrations from the disability certification guidelines pertaining to haemoglobinopathies that I reproduce below depict how subjective experiences form the basis for this assessment, leaving considerable room for expert—both medical and bureaucratic—interpretive flexibility. (Despite the legal authority of these guidelines, blood disorder patients have reported instances where they have had to demand disability certificates from physicians who refuse to recognise their disability status despite constitutional sanction.) The 2018 disability certification guidelines stipulate a ‘dynamic’ process for the evaluation of blood disorders owing to the biological causality that ‘these diseases are progressive in nature’ (Government of India, Ministry of Social Justice and Empowerment 2018, Chapter VII, Clause 26.2). For instance, in the case of sickle cell disease the guidelines state that ‘the disability changes over time and therefore shall be measured longitudinally’ (idem, Clause 32.1). It is this temporal contingency that was originally interpreted in the 2018 disability certification guidelines to dictate the necessity for annual renewal of disability certificates for haemoglobinopathies (a stipulation that became the object of ardent contestation by haemoglobinopathy patient communities as described above). Below are two descriptive charts and their corresponding ascriptive tables that contextualise this co-production in relation to haemoglobinopathies:

- 0.- Homozygous sickle cell disease but asymptomatic – but has got mild pallor (HCT 30) and splenohepatomegaly and diagnosis confirmed by Hb electrophoresis;
- 1.- Sickle cell anemia such as HbSS, compound heterozygous (HbS/_0) thalassaemia, HbSD, and HbOArab, anaemia that is severe and chronic, with persistent haematocrit of 26% or less, and symptomatic, requiring blood transfusions to maintain the HbS level 30% and TRANSFUSION DEPENDANT and symptomatic as per New York Heart Association (NYHA) more than class 2;
- 2.- Above plus Painful crisis due to blood clots in blood vessels at least three times in the past five months (vasoocclusive crisis or thrombotic crisis);

11 For prior disability evaluation guidelines in India, see: GUIDELINES & GAZETTE NOTIFICATION (Committee under chairmanship of DGHS, GOI) issued by the Ministry of Social Justice & Empowerment, Government of India, Regd No. DL33004/99 (Extraordinary) Part II, Sec. 1, June 13, 2001.

- 3.- Above plus Hospitalization beyond that of emergency care at least three times in the past 12 months (could be due to aplastic episodes, haemolytic crisis, strokes, heart problems, kidney failure or pneumonia);
- 4.- Above plus Functional impairment caused by sickle cells that meet another disability listing due to avascular necrosis, osteomyelitis, and bone infarction of multiple joints, stroke and transient Ischemic Attack (TIA), leg ulcers – should be referred to multi-disability board;
- 5.- Above plus Permanent Loss of spleen function or chronic hypersplenism with recurrent infections (more than 3 in last 6 months);
- 6.- Above plus Complications like impaired neuropsychological function with abnormal cerebral MRI scan, sickle nephropathy, sickle cell lung disease, bilateral proliferative retinopathy leading to loss of vision and chronic liver disease;
- 7.- Above plus Impaired cardiac function due to end organ damage measured by functional ECHO Cardiography;
- 8.- Above plus Sickle cell anaemia with BT (blood transfusion) associated complications due to infections like HBV, CMIV, HIV, HBC, etc.

Chart 1. ‘Severity score’ for sickle cell disease, reproduced from the 2018 Disability certification guidelines.

At level	Disability should be
0, 1	< 40%
2	40–50%
3	51–60%
4	61–65%
5	66–70%
6	71–75%
7	76–80%
8	81–85%

Table 1. Disability grading, in the 2018 Disability certification guidelines, Chapter VII, Clause 36.

- (a) Mild anaemia refractory to iron supplementation, and microcytic hypochromic with hepatosplenomegaly and confirmed by Hb electrophoresis but asymptomatic and no BT# requirement;
- (b) Thalassaemia Major with monthly BT# requirement but Haemoglobin maintained at 10 – should receive some benefit like time out, special leave, social security and free treatment-TRANFUSION DEPENDANT and exertional dyspnoea on walking few yards more than class 2 as per NYHA and AHA;
- (c) Above plus Thalassaemia major with monthly BT# with signs of bone marrow hyperplasia and osteoporosis decided by bone DEXA scan
- (d) Note at this stage should be seen by multi-disability board and should be seen by ortho-paediatrician;
- (e) Above plus Iron chelator requirement osteoporosis and Serum ferritin less than 1000ng/ml;
- (f) Thalassaemia major as in level 4 plus with Bimonthly BT# requirement and all the above;
- (g) Thalassaemia major > than bimonthly BT requirement with features of hypersplenism and more than 250 ML packed cell transfusion/Kg per year plus features of level 5;
- (h) Thalassaemia major with splenectomy with infection and plus features as in level 6;

- (i) Thalassaemia major with features as above at level 7 plus haemosiderosis and serum ferritin level > 1000ng/ml and with multi organ failure decided by Echocardiogram, LFT and GTT;
- (j) Thalassaemia major with features at level 8 plus with BT associated infections like HBV, CMIV, HIV, HBC, etc.

Chart 2. ‘Scoring system for assessment of disability’ in thalassemia, reproduced from the 2018 Disability certification guidelines.

At level 1	< 40%
At level 2	41–50%
At level 3	51–60%
At level 4	61–65%
At level 5	66–70%
At level 6	71–75%
At level 7	76–79%
At level 8	80–85%
At level 9	>85%

Table 2. Disability grading in the 2018 disability certification guidelines, Chapter VII, Clause 38.

Regardless of subsequent amendments to these guidelines in response to patient demands, what remains noteworthy in the criteria for measuring ‘benchmark disability’ for haemoglobinopathies is that the need for recurring medical evaluations is co-produced (Jasanoff 2004) with a legislative interpretation of the ‘progressive’ nature of blood disorders that deny individuals with these conditions a ‘permanent disability’ status. Notwithstanding the technical terminology of disease symptoms, Charts 1 and 2 showing severity scores and the corresponding Tables 1 and 2 showing disability grading demonstrate how numerical ranges become ‘stand-ins’ (Horrocks 2019) for the bodies living with blood disorders in India.

The charts above delineate progression of disease, by using a set of symptoms that characterise stages of disabled embodiment. They are ascribed to levels ranked on an ascending scale of severity. In the corresponding tables, these levels are then graded by ascribing them with a percentage range specifying the degree of disability. Such ascriptions have no direct correlates in medical diagnosis and are purely heuristic policy devices adopted to facilitate practical governance. The sets of symptoms and their corresponding percentages thus together standardise (Bowker and Star 1999) otherwise non-quantifiable experiences of disability for the purposes of implementing policies of affirmative action. It is important to note here that the 2018 disability certification guidelines for determining ‘benchmark disability’ has been arrived at through an iterative process of consultations between expert committees and policymakers (2018 disability certification guidelines, 63). In the construction of ‘benchmark disability’, therefore, expert opinion, political reasoning, and subjective experiences of disability converge to

standardise the process of disability certification in India. Bioconstituting haemoglobinopathies as ‘benchmark disabilities’ can thus be seen as a synergistic moment of cooperation between biomedical evaluation and the legislative machinery. It builds upon patient advocacy for recognition of these disorders to reorder the constitutional relationship between the Indian State and Indian citizens affected by blood disorders—even as these reorderings tending towards substantive justice have taken place incrementally over time.

Nevertheless, the mechanisms that are put in motion as a result of such reorderings between the State and its differently-abled citizens generate contingencies that are hard to wholly anticipate. In the case of inherited blood disorders, there also exists a simultaneous reality of biomedically mapping blood disorders onto ‘caste-ized’ social groups in India (Chattoo 2018; Egorova 2010).

As I elaborate in the concluding section, one consequence of the ‘frictions’ that arise from the inevitable interactions between co-existing epistemic ontologies of haemoglobinopathies is that for communities who are already subject to caste-based structural inequalities (Omvedt 2020), the requirement for percentage disability certification to access legislative guarantees of affirmative action end up instead further aggravating trenchant problems of socioeconomic marginalisation. For disabled individuals from marginalised communities, often low literacy levels and financial situations that prevent them from taking a day off work to obtain certification mean that complex policy directives become intimidating bureaucratic hurdles. Such mechanisms of marginalisation must be paid close attention to in life-affirming legal re-orderings of sociopolitical institutions. Indeed, another appeal made by a physician in the Indian parliament on 21 December 2017 draws attention to the difficulty arising from the need to produce disability certification, in this case for accessing a legislatively guaranteed disability stipend. The physician writes in the appeal, ‘The most important point is that these disabled persons find it very difficult to obtain the certificate to avail the disability stipend, which is the scheme of the Central Government.’ New forms of exclusions therefore may be generated as ‘unintended consequences’ (Parvin and Pollock 2020) in conjunction with the construction of co-produced categories resulting from constitutional reorderings. I argue that such contingencies necessitate in turn a measure of bioconstitutional reflexivity that is receptive to citizens’ interpretation of legislative restructurings. It is in view of these complexities that I read the bioconstitutional moment of certifying blood disorders through the standard of ‘benchmark disability’ as a moment of reckoning for biological citizenship.

Conclusion: Grounding certificate anxieties

In February 2022, eight months after I concluded my ‘patchwork ethnography’ on certificate anxieties and reflexive bioconstitutionalism, restrictions due to the COVID-19 pandemic were eased to some extent, making it possible for me to travel to India to conduct my independent doctoral dissertation research on sickle cell management. During a field visit to a remote *Adivasi*¹² village in the southern Indian state of Tamil Nadu, I interacted with a 35-year-old *Adivasi* woman affected by sickle cell disease, who I will call Kamala. At the time, I was collaborating with a local non-governmental organisation (NGO) which had asked me to conduct a survey to investigate the status of sickle cell patients in the village. One of the questions included in the survey asked about access to a disability stipend or disability benefits. Although distant *Adivasi* communities are often cautious about engaging with such academic instruments as social surveys, the issue of access to disability benefits, locally known as ‘pension’, elicited an uncustomarily descriptive response from Kamala, who narrated her certificate anxieties in the following manner:¹³

No! I don’t receive disability benefits. But I have applied for the pension. I have not got it yet. Now, I am arranging for the additional documents that I was asked to show to the government officer. I have already applied [for the disability benefit] 2–3 times. The problem is that I got my disability certificate from the hospital run by your NGO. Government offices are not accepting these documents, and they say that signatures from a government doctor is required. I went [to the nearest district with a government hospital] one day. But that day, the doctor was not there, and they sent me home. After that, I could not go another time. I have no money for going on multiple trips.

This chance organisational survey conducted months after the formal completion of my research described in this article made it possible for me to witness how the object of my critique here—that is, the legislative requirement for certification of disability due to blood disorders to permit access to affirmative action—manifests in real-world circumstances. In this case, the real-world circumstances are the *Adivasi* lifeworlds at the margins of the Indian State that Dongre had earlier described to me. A considerable degree of subjective interpretation is involved in deciding who receives a disability certificate, and these decisions are mediated at different levels by doctors and local bureaucrats. For an *Adivasi* woman like Kamala with very little education, navigating such arbitrariness is also costly owing to her, and her community’s, depressed economic status. Kamala’s certificate

¹² Also referred to as ‘tribal’; the use of this representative term is no longer considered acceptable.

¹³ The survey was conducted in collaboration with an English-speaking *Adivasi* community member. The quote is a translation from the Paniya oral *Adivasi* language as provided to the author by the collaborator.

anxieties in this instance manifest as feelings of uncertainty regarding access to supposed constitutional guarantees. In a separate conversation, another sickle cell patient from a different region in India shared with me that some uninformed doctors refuse to issue disability certificates to haemoglobinopathy patients as their disability is not physically evident and is hence ‘invisible’. These contradictory findings on the actual processes of disability certification resonate with Sumukhi’s certificate anxieties regarding arbitrary and heuristic decision-making by experts, which are arguably laced, furthermore, with subtle operationalisations of class, caste, and ethnicity-based power relations.

In this article I have investigated the ‘frictions’ between bioconstitutionalism and biological citizenship surrounding disability certification for blood disorders in India that generate possibilities for reflexive bioconstitutionalism. I contextualise the practical difficulties arising from standardising measurements for determining the percentage of disability due to haemoglobinopathies through the awarding of the status of ‘benchmark disability’, and the certificate anxieties that arise from these difficulties. I argue that these anxieties generate productive tensions as contestations that reiterate the importance of the lay expertise (Lindén 2021) of concerned citizens in democratic decision-making, an issue that has long been a focus of STS scholarship (Collins and Evans 2002). Yet, my objective in this article has been to demonstrate that certificate anxieties are more than manifestations of embodied and situated expertise; they are also articulations of rights that are negotiated within the public–political sphere formed at the interface of constitutionalism and citizenship. These articulations not only demand participatory rights in the epistemic processes of bioconstitutional reframings that shape the collective futures of citizen communities; they also reframe the discourse on biocitizenship rights based on the particularities of diverse social situations. Certificate anxieties can therefore be read as critical subjectivities that stress the democratic imperative of aligning State institutions and legislative machineries to citizens’ constitutional expectations.

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