Chapter 3
Disorder, Disability, Difference: (Re)presenting Autism in India

Shubhangi Vaidya

Abstract The paper traces the emergence of autism as a salient category in India, drawing attention to the diverse strands, including biomedical and psychiatric research and practice, activism and advocacy in civil society, and personal narratives and creative expressions that have contributed to the discourse around autism in India. It locates these discourses within the 'glocal' moment of circulation of information and experiences, and the construction of the category as disorder, disability and difference. It makes a case for interdisciplinary understandings of disorders and disabilities in order to obtain a holistic picture of lived experiences and their sociocultural underpinnings.

Keywords Difference · Autism · Literature · Representation

Introduction: Contextualizing Autism in India

The emergence of autism as a salient category in the disability landscape in India is of relatively recent provenance. The category of autism has evolved over the past two and a half decades from a 'rare' disorder addressed within hospital settings to a developmental disability that has found inclusion within India's new rights-based legislation, the Rights of Persons with Disabilities Act (2016). An understanding and appreciation of autism as a human difference, a valid and valuable way of being-in-the-world, is also gaining ground, as the condition has become more visible and activists and self-advocates have begun to emerge and participate in the discourse. These understandings of autism as disorder, disability and difference are not mutually exclusive or linear, rather, they inflect and impinge upon each other in a variety of ways. As the parent of a young adult with autism and a scholar with research interests

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S. Vaidya (✉)
Associate Professor and Director, School of Interdisciplinary and Transdisciplinary Studies, Indira Gandhi National Open University, New Delhi, India
e-mail: svaidya2404@gmail.com

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in the interdisciplinary domain of disability studies, I have been engaged with, and a participant in these discourses, and thus bring on board my own subjectivity and reflexivity into my analysis.

This paper will discuss the framing of autism in India in biomedical and psychiatric research and practice; activism and advocacy in civil society largely driven by family members of persons with autism, and representations of the condition through selected narratives that open up the discussion on the lived experience of autism, including poetry, parental narratives and cinematic representations. This broad sweep is intended to open up the category of disability to multiple understandings and interpretations, and through diverse yet intersecting accounts, underscore the contested nature of (dis)ability, and the power relationships that are inherent within it. They also bring to attention the evolution of the disability discourse in India and the attempts by different stakeholders to present their side of the story, create communities based upon shared experience and de-stigmatize the experience of disability.

Representations of autism have largely been in the context of discourses around personhood and sociality in highly industrialized Western sociocultural contexts; Straus (2010), for instance, interprets it as a pathological manifestation of the highly prized cultural value of autonomous individuality which then translates into painful solitude, loss of community and extreme isolation (536).

In non-Western contexts, autism presents a fertile ground for medical sociologists, anthropologists and cross-cultural psychiatrists to unpack how local understandings and cultural constructions of normalcy and 'deviance' interact with global discourses and practices. Such studies draw attention to the historical and sociocultural contexts within which disorders and conditions are defined and made natural. Autism in India presents a rich site for understanding how meaning-making takes place in the context of disorders and disabilities.[1] A country with a population in excess of 1.3 billion, an ancient civilizational history, a multi-cultural, multi-ethnic and multi-lingual social fabric and a vibrant democratic polity, India is, to use a cliché, a curious contradiction of tradition and modernity.

Current understandings of disability in India draw upon both deeply resonant cultural images and values, Western-inflected categories and practices as well as contemporary, global-rights-based understandings, with India being a signatory to the United Nations Convention on the Rights of Persons with Disabilities (The United Nations Convention on the Rights of Persons with Disabilities 2006). The deeply entrenched ideas of *karma-phal* (consequences of past deeds), *seva* (service, particularly for vulnerable people) and *daan* (charity for earning religious merit) rub shoulders with biomedical notions of disease and cure and contemporary rights-based discourses. This co-existence of the medical and religious models of disability

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[1] See, for instance, Daley's (2004) study on symptom recognition and diagnosis based upon interviews with 95 families from different parts of India and her later study of adults and their families in Delhi (Daley et al. 2014; Grinker 2007; Feinstein 2010), whose books have sections on autism advocacy in India; Mehrotra and Vaidya's (2008) comparative study of intellectual disability in Haryana and Delhi; Desai et al. (2012) and Divan et al's (2012) study of families of autistic children in the western state of Goa; Sarrett's (2015) research with families in the southern state of Kerala; Vaidya's (2016) ethnography of families with autistic children in Delhi.

is reflected in the eclectic mix of remedies resorted to in order to cure disabilities, including visits to shrines and religious centres, and multiple systems of treatment.

The work of scholars like Miles (2001, 2011) draws attention to disability histories from antiquity and nudges contemporary practitioners and stake-holders to delve into the riches and insights of their society's past rather than uncritically adopting Western theories and practices. He calls for 'historical action research'; 'listening long to cultures and voices of Asian people; listening to disabled Asians; reflecting on disability ethics and choices with Asian colleagues; and strongly supporting those who are looking deeper and taking the longer view' (Miles 2009: 81–82). The edited volume by Rao and Kalyanpur (2015) similarly situates South Asian experiences of disability against the unique historical experiences of colonialism and globalization and draws attention to cultural narratives regarding disabled bodies, specific indigenous constructs and the uncritical transfer of Western expertise that creates further sites of discrimination, as in the chapter by Maya Kalyanpur which addresses the classification and assessment of disabilities of Indian children based upon Western categories. These perspectives are particularly relevant in the context of conditions like autism, particularly against the backdrop of urbanization, globalization and transnational flows of people, products, services and ideas that have contributed to and complicated the narrative around autism in India. The availability of the Internet and the proliferation of social media platforms across geographical boundaries have opened up communication and information sharing as never before. A steady stream of information about research, teaching strategies, alternative therapies and biomedical interventions has become readily available to a growing section of English-knowing middle-class people. An unregulated 'therapy market' offering untested, unvalidated treatments and 'cures' has also come into existence.[2] This may result in financial hardship for families keen on curing their children and inadvertently subjecting the person with autism to invasive and potentially dangerous procedures.

This paper focuses primarily on urban, middle-class, English-speaking spaces, within which the author is also located, and thus does not claim to represent the realities experienced by large sections of the population who still struggle to access basic social goods like nutrition, health care and education.[3] It thus will provide only a partial picture, but one which, I argue, has proved deeply influential in shaping public perception and policy. The identification and treatment of autism in India remain a predominantly urban phenomenon and access to early identification and intervention has a strong class dimension. I begin by briefly situating autism within

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[2] A recent example is the offering of stem cell therapy by some private clinics as 'treatment' for autism at extremely high costs. Medical opinion on its efficacy is divided and parent groups like the Forum for Autism in Mumbai have mobilized public opinion against its unregulated use and promotion. See https://timesofindia.indiatimes.com/city/navi-mumbai/no-proof-that-stem-cell-therapy-can-cure-autism/articleshow/58198459.cms accessed on 26 December 2017.

[3] One of the legacies of two centuries of colonial rule was the establishment of English language education, which acted both as a means of mobility and a tool of discrimination. In contemporary India, English language education accords the opportunity to break free from oppressive social hierarchies and gain entry into the 'modern' world of opportunities fostered by the Information Technology revolution.

the biomedical and psychiatric research literature in India and the genesis of the ‘autism sector’ in urban India.

Autism in India: An Historical Verview[4]

Tamara C. Daley’s article on the website of the Delhi-based NGO Action for Autism informs us that contrary to popular belief, autism is not new in the Indian literature. This is hardly surprising, considering the history of colonial medicine and the familiarity of Indian practitioners with Western psychiatry and psychology. Daley cites a report by the Viennese paediatrician A. Ronald, working in Darjeeling at the time, and published in the *Indian Journal of Pediatrics* in 1944, which she believes to be probably the first reference to autism or the pervasive developmental disorders. Presenting an overview of the detection, causes, types and treatment of ‘abnormal’ children, Ronald discusses various types of difficult children, including ‘deviant’ and ‘frightful’ ones. He also offers a description of a particular kind of difficult child, and its ‘precocious’ behaviour which has a strong resonance with some of Leo Kanner’s case descriptions in his landmark paper in 1943 Kanner (1943).

The precociousness of a child is not always limited to specific spheres…it extends to the whole of mental personality…such children are quite different from others in respect of behaviour, speech, movements and work. The child-like conduct has partly or fully disappeared, the mental attitude of such a child becomes somewhat strange and repulsive…such children are no longer child-like; they do not play and are not cheerful. Partial precociousness shows itself in the development of a particular sense, for example, musical sense, calculations, mechanical handling and so on. In this group is included the so-called prodigy…[5]

Whether the above account refers to the cluster of symptoms that define autism is a matter of speculation. From the late 1950s onwards, articles on the pervasive developmental disorders, using the terminologies of the day, began to appear. Daley (2004) notes the multiplicity of terms used to denote the condition, including childhood schizophrenia, infantile autism, early infantile autism, savant syndrome, childhood psychosis, pervasive developmental disorder and disintegrative psychosis (1325). Malhotra and Shah (2017) cite a publication by Bassa (1962) as the first Indian case report on autism. They observe that the ‘history of autism’ in India is marked by ‘initial sporadic efforts at clinical descriptions and research followed by a more sustained progress in clinical services, research, and policies’ (1). They note that while there were a few publications referring to ‘infantile autism’ in the 1960 and 1970s, a steady flow started only after the 1990s. A report of 17 children diagnosed autistic by Erna Hoch (1967) is regarded as an important early study. According to Kapur (2011):

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[4] Some of the ideas in this and the following section have been discussed in Vaidya (2016).

[5] Quoted from Daley, n.d. http://www.autism-india.org/research-autism-india.php accessed on 20 December 2017.

> This classic report consisted of acute phenomenological observations and aetiological speculations. To paraphrase Hoch, disturbances in the close relationship between mother and child may occur either because of the child's excessive sensitivity or a faulty maternal attitude. As such disturbances occur fairly early in infancy, they may leave a permanent weakness of what one calls the 'ego boundary', which is the ability to identify oneself as a separate unit which faces the outside world (p. 110).

Kapur also cites her own research with six children, conducted in 1986, in which she refers to their autism as an 'illness precipitated by severe psycho-social stressors' (2011, p. 110). Malhotra and Vikas (2005) and Naik (2015) indicate that autism as a diagnostic category has had a presence in the Indian medical landscape, citing a number of research studies mainly in hospital settings and with cohorts from special schools. Daley and Sigman's (2002) study of the diagnostic conceptualization of autism among Indian psychiatrists, psychologists and paediatricians also indicates the presence, albeit marginal, of autism in medical circles.

However, the lack of familiarity of family physicians and paediatricians, usually the first port of call in the case of any developmental delays, with the diagnostic category and nosological systems like the ICD and DSM, is believed to be reason why the condition is routinely undiagnosed or misdiagnosed; even to this day, it is routinely subsumed in the category of 'mental retardation' (a term still in use in India) or mental illness. The perception that autism is a rare, 'Western' condition that did not merit any serious attention or policy intervention was also well entrenched until recently, and efforts to introduce autism-specific policies and services met with resistance by those professionals who continued to view it as a subset of intellectual impairments or mental retardation.

The period from the late 1980s and early 1990s onwards saw an intensification of interest in the category of autism globally, as growing numbers of children were diagnosed with the condition, particularly in the Western countries. This had an impact upon autism awareness in India as well, as information about the condition became more readily available. This resulted in an intensification of activities in terms of awareness raising, creation of services, legislation, policy and capacity building. The driving force behind these developments was the emergence of parent-led organizations primarily for advocacy for children and adults with autism and other developmental disabilities, and their families. Bound by the common circumstance of a loved one's disability and the lack of availability of services and social supports, some parents and caregivers started to come together to help their children and build their own capacities. Much like parental activism elsewhere, these parents-turned-activists donned the mantle of teachers, trainers, advocates, lobbyists and institution-builders, and inaugurated the 'developmental disabilities sector' in India.

From 'Disorder' to 'Disability': Autism, Families and Advocacy

Expanding what Ginsburg and Rapp call the 'social fund of knowledge about disability' (2010: 239), family-driven organizations extended the scope of kinship outside the ambit of the biological family to the larger realm of public culture, and made their experiences and learnings available to the wider community. Action for Autism and Tamana, both based in Delhi, were amongst the first organizations to address the needs of persons with autism; since then, nearly 80 centres and special schools working with persons with autism and developmental disabilities have come into existence (www.autism-india.org). One of the important goals of these organizations is the provision of education and training for children with autism, as they are routinely denied admission to regular as well as to special schools catering to children with other disabilities. The social stigma that surrounds conditions like autism also extends to the family; therefore, it is quite common for parents to 'hide' children from public view and keep them confined within the home, further exacerbating the stigma and shame. The mother, in particular, is subjected to judgmental attitudes and blame, especially if she happens to be in outside employment (Vaidya 2016).

Action for Autism in Delhi, established in 1991, is widely regarded as a pioneer in the field of autism advocacy and service provision in South Asia (see Grinker 2007; Feinstein 2010; Mehrotra and Vaidya 2008; Vaidya 2016). From its birth as a small group of parents struggling to find a place for their children with autism to learn and grow, it has developed into a multi-tasking centre of activity which conducts early identification and assessment, parental counselling and training, awareness raising and service provision, and research and advocacy. It conducts teacher-training programmes, runs a model school, a vocational training centre for adults and has recently started *Ananda*, a home for adults. It has played an important role in the formulation of legislation and policy concerning autism in India. In the process, it succeeded in creating awareness about the disability in both professional and lay circles. One of the early projects undertaken by the organization in 1998 was an 'awareness project' with paediatricians all over the country, providing them with materials and information that would help them in early diagnosis and intervention.[6] Much of the understanding around autism that organizations like AFA helped to create came from their hands-on experience as parents and teachers, and their efforts to obtain information and expertise at a time when both were in scarce supply. Recognizing the crucial role of the Indian family as the sole source of support for the person with autism, AFA started an intensive training programme for parents to help them better understand their child's autism and advocate for their child.[7] Some of these parents would go back and establish schools for unserved children with autism in their own home towns.

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[6] Details of the project are available on http://www.autism-india.org/professional-awareness.php.

[7] See Brezis et al. (2015) for an analysis of parental attitudes before and after attending the 3-month Parent-Child Training Program (PCTP) at action for autism.

The 1990s was also the period when the Disability Rights movement (DRM) gained traction in India, influenced by rights-based discourses established in other social movements like the women's, environmental and Dalit movements (Mehrotra 2013). One of the major landmarks in this period was the enactment of a comprehensive legislation to safeguard the rights of persons with disability, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1995, which identified seven categories of disabilities that qualified for state support and entitlements. However, autism was not included in the list of identified disabilities, even though the categories of 'Mental Retardation' and 'Mental Illness' found a place.

Autism found inclusion in The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999) which essentially dealt with the issues of social inclusion and provision of care within the community for persons with high support needs, and the issue of guardianship for individuals who may require support and assistance take care of their needs or make decisions.[8] However, on the ground, the status of autism continued to remain that of an outlier in the disability sector; children with autism continued to be denied placements in regular as well as special schools and were routinely denied an official disability certificate unless they met the specified degree of 'mental retardation', which was included in the PWD Act. The lack of this document deprived many people of access to the minimal facilities provided by the state, causing further hardship to affected individuals and their families.

Meanwhile, in 2006, the United Nations Convention for the Rights of Persons with Disabilities was adopted, and India became one of the signatories. It was thus duty bound to enact legislation in compliance with the convention, and so the process of drafting the new legislation was initiated in 2009, with a considerable role played by parent activists. After several rounds of drafts and considerable delay on account of a change in the national government after the General Elections of 2014, The Rights of Persons with Disabilities Act was passed by the Indian Parliament in December 2016. It incorporated a list of 21 disabling conditions, including autism. The inclusion of autism within rights-based law is a major moment, securing recognition and creating the conditions for service provision and social inclusion. At the same time, the inclusion of such a diverse range of disabilities within a single legal framework presents a host of challenges, as the debate around legal capacity and guardianship testified.

There has also been a growing international interest in autism research and advocacy in India. International charities like *Autism Speaks* have registered their presence in the Indian autism sector, funding research projects and conferences and partnering with governments and other stakeholders across South Asia. 'Light it up Blue',

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[8] The debates around guardianship of certain categories of persons with disabilities and the issues of legal capacity and decision-making have been ongoing ones within the disability movement, and these assumed a particularly sharp edge during the drafting of the new disability legislation in response to India's ratification of the UNCRPD (see Ghosh 2016, p.15 and Vaidya 2014 for different viewpoints).

Autism Speaks' initiative to commemorate the UN sanctioned World Autism awareness day on April 2, elicits an enthusiastic response amongst local autism groups; the 'lighting up blue' of public buildings and the social media campaigns on the day are seen as opportunities to create public awareness and gain visibility.

The 'internationalization' of autism advocacy raises important issues with regard to the import of Western perspectives which may be losing traction in their own contexts.[9] At the same time, these engagements provide opportunities and research grants to local professionals and researchers to develop good practices and strategies for their own communities. While there is an urgent need for more research, global collaborations and cooperation, the opportunity to develop a uniquely South Asian disability discourse and practice runs the risk of being subsumed within global trends. Within the autism sector, in particular, Western templates for identification, intervention, education and care need to be revisited in the light of cultural and social realities. Developing materials and methodologies keeping in mind local needs and understandings is critical. For example, Grinker et al. (2015) demonstrate a methodology of cross-cultural translation of outreach materials (Autism Speaks First Hundred Days Kit) into Korean through a careful study of local explanatory models of the condition, causation and care. In the Indian context, structural factors like poverty, caste, class and gender also play a critical role in determining who gets access to scarce resources and who falls through the cracks.

Having provided a broad overview of the trajectory of autism as a salient category, the following section will present selected literary narratives that represent the experience of autism. The devaluation and objectification of the disabled person and the family as broken and flawed can only be resisted by an empathetic understanding that foregrounds their positions as subjects and respects difference.

Life with Autism: Some Experiences and Expressions of 'Difference'

There is a large and growing corpus of autism narratives in the West, and increasingly, narratives from India are finding their space, both in print and online. In this section, I look at two parental narratives on the experience of raising a child with autism. The first is by Merry Barua (2007), founder of Action for Autism, reflecting upon her journey with her son who was diagnosed when autism was virtually unknown in India. The second is by Madhusudan Srinivas (2016) father of a young adult with autism, which highlights the challenges of raising a child with significant impairments in contemporary urban India. I then introduce the poetry of Parul Kumtha, a parent-activist from Mumbai, who attempts to put herself in the shoes of the autistic subject

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[9] The trenchant criticism of Autism Speaks by self-advocates and families of adults with autism in the U.S. is unlikely to find a resonance in low resourced countries where the issues of early identification, appropriate intervention and parental empowerment are the major concerns, and where self-advocacy is at a nascent stage.

and give voice to their experiences. The fourth writer is an autistic individual, Tito Rajarshi Mukhopadhyaya, whose poetry takes the reader into the realm of embodied autistic experience and opens up new ways of looking at (dis)ability. These four sets of narratives reveal multiple dimensions of the experience of autism from different standpoints.

Merry Barua's (2007) reflexive account of her experiences in bringing up her son Neeraj, diagnosed with autism in the 1980s, when the condition was virtually unknown to all but a selected few doctors, takes the reader through the slowly dawning realization of a child's atypical development, the confusion and self-doubt about one's own capacities as a parent and the helplessness and powerlessness of being handed a diagnosis without any guidance on how to help the child. She describes her journey towards 'complete acceptance and unconditional love' (36) through some of the most difficult phases of her son's growing years, especially during his late teens, when he experienced "a rage, depression, anger that he was helpless to control, and which expressed itself in exceptionally challenging behaviour". For six months it was like living with a caged tiger' (36). Her account does not demonize her son, rather, his humanity is emphasized at every stage. His difficulties in controlling his feelings or understanding clearly the consequences of his actions are viewed by Barua with the lens of acceptance of the person that he is, rather than judgment on what he ought to have been. She acknowledges her son as a complete human being in his own right, a source of love and joy, and the motivating factor for what was to become her larger mission, the creation of the organization Action for Autism (referred to earlier in the chapter): 'I started the work that I do now knowing that I did not want other parents to go through what I did after Neeraj's diagnosis: the uncertainty, the blame, the misinformation, the lack of services' (39). Barua ends her account by highlighting both, the uncertainty around autistic futures and the hope that she would be able to set up services that would look out for her son and others like him. The account highlights not just her own tolerance and acceptance of her son's challenging behaviours but also the domestic and social contexts within which they are expressed and resolved. Neeraj has a social life, albeit through his mother; he attends picnics and enjoys community events like the crowded Durga Puja. It also underscores the pervasive mother-blaming in the context of parenting a child with disability, and the role of faith and spirituality in coming to acceptance and equanimity.

Jerry Pinto's edited anthology 'A Book of Light' (Srinivas 2016) comprises essays by family members of persons with psychiatric disabilities. Questioning the myth of the 'normal home' the book looks at families whose lives are centred around a single member, a loved one 'with a different mind' (the subtitle of the book). One of the authors, Madhusudan Srinivas, writes about the everyday challenges of parenting an autistic child with severe impairments, as he lets the reader get a look into life with Abhimanyu, his son, presently in his 20s. Srinivas (2016) writes with candour of the early years when the child's inexplicable bouts of crying would be so intense that they would put him in the car and drive all over the city just to calm him, the 'crippling embarrassment' at his odd behaviour in public places, and the consternation caused by his seizures and loss of bladder control. He writes of the setbacks when Abhimanyu experiences a seizure; the anxious re-jigging of medications and change of doctors; his own exhaustion and sleep deprivation.

And yet the life we lead, bringing up our child, a young man who hasn't spoken a clear full sentence to us in all the years since he was born, and then diagnosed with autism at nearly three—our precarious life together—is also supremely happy. I would not trade it for any other even if he is not and will never be like other children; in some ways, he will always be a child (99).

However, despite this framing as a permanent child, Srinivas points out that Abhimanyu is a young man, and does show 'flashes of his growing will' (100). His taste in music is well developed, and he shares a love for it with his parents. He questions the stigmatizing of the disabled other and the homogenizing tendencies of society which attempts to eradicate difference. He writes.

Most of our children haven't demanded anything of us, ever. It's we who end up demanding a hell of a lot of them in our endeavour to meet society's norms. To make the differently abled as non-different and as indistinguishable as we can. To gain 'acceptance'- in the family, the home, the housing society, the mohalla, the street, the main road, the mall, the multiplex, the metro line, the market, the world at large (100).

The essay addresses the critical question of what constitutes a good or worthy life, and the need for an ethics of care. Importantly, it highlights the need for a caring community- family, friends, neighbours and domestic staff-and the wider world in which the father makes conscious attempts to include the son, "making bridges online and off: journalism and autism for me, have gone hand in hand" (99).

While Srinivas's narrative is from the perspective of the caregiver attempting to assert and affirm the personhood of a vulnerable child, Parul Kumtha's 'performance poetry' assumes the voice of the silenced autistic subject. Kumtha, the mother of an adult with autism and one of the founding members of a Mumbai-based parent group, attempts to gain an insight and represent the experiences of persons with autism in a world determined to discipline, regulate and crush their selfhood. The poems, extracts of which are quoted below, begin with the question 'Why' and are based on incidents faced by persons with autism and their families, while negotiating the world of therapy centres, schools and other institutions in Mumbai.[10]

The poem '*Why I cling to you*' explores the anxieties of a young man and his attachment to his mother.

I am a man now, taller than papa, broad in the chest and deep in the voice.
Do you remember when I was little and I crawled to sit outside the toilet door
while you bathed or crapped or peed?
Do you remember how I howled until my lungs ached and my body racked? I do.
I remember that you spoke to me from the other side of the door, tried to calm me…
but I did not know that you existed on the other side - I couldn't see you, so you didn't.

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I always wait for you, mama and I can't be at peace, not knowing when you will be back.

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[10] Extracts of Parul Kumtha's poems are reproduced with the permission of the author.

> *Because you know what I eat and when, what I wear and how, what I do and why.*
> *You are my interpreter to the world…and so, I can't let you out of my sight.*
> *It worries me… It worries me ---- what if you are gone too?*

The final lines of the poem respond to the advice often given to mothers to 'distance themselves' from adult children because they have 'men's needs' and thus potentially constitute a sexual threat.

> *Mama, please don't distance yourself from me - you are my bridge to the world!*
> *That is why I cling to you, despite being broad of chest and deep of voice.*
> *Not because I crave carnal, physical proximity.*

In the poem *Why am I not ME by any other name?* the issues of choice, identity and selfhood are raised. The subject pleads for the right to be known by the name of her choice, 'Bubbly', her family's loving name for her, and not 'Jui', her 'official' name, which she associates with being sent away to an institution.

> *My family couldn't cope with me last year.*
> *That's when I was sent to an institution to calm me down. I hate the place.*
> *It was full of 'don'ts'. "Jui, don't do this, don't do that, don't, don't, ---- don't…."*
> *When I returned home, mama and papa cried.*
> *They said that I was a third of myself, sunken eyes and furtive look*
> *when I surfaced from the drugged stupor in which I was maintained at that place.*
> *"Bubbly", my mama said and hugged me tight as she sobbed into my shoulder.*
> *Yes mama, I am your Bubbly and I want to always be your Bubbly.*
> *Please don't send me to the Jui prison again.*
> *I am not Jui anymore. I can't be Jui anymore. Don't anybody, ever call me Jui again.*
> …………..
> *I read the tabloids you know,*
> *I read the tabloids you know? full of stories about rich and famous people who have changed their names to change their destinies!*
> *Why won't you allow me to change mine?*

Kumtha's poetry offers a powerful critique of the dehumanization of the disabled subject and the relationships of power and control that obtain between persons with disabilities and the 'professionals' who deal with them. The following excerpt from '*Why I sit under my desk and not at it*' underscores the lack of understanding about disability, and the often abusive disciplining strategies to extract compliance and enforce order.

> *Every day I come to school, clutching my fear to my heart, afraid that it will be my turn today*
> *Every slap that whistles past my ear and lands on my classmate's cheek resounds in my brain*
> *Every command that you bark at others ricochets off the walls and booms at me*
> *Every day I struggle with my autism: struggle to make sense of your world*

Perhaps one of the most powerful voices to emerge from the autism spectrum and profoundly challenge received understandings about the abilities of ‘severe’ autistics is Tito Rajarshi Mukhopadhyaya. Born and raised in Mysore and Bangalore, Tito, who has fairly severe impairments, was taught by his mother Soma through a unique teaching method, the Rapid Prompting Method, that she devised. This strategy enabled Tito to communicate and write independently. By the age of 12, Tito had published his first book, *Beyond the Silence*, which was later published in the US as *The Mind Tree* (Savarese 2010). Tito and Soma were invited to the US at the instance of Portia Iverson, the parent of an autistic son, and co-founder of the organization Cure Autism Now (CAN), which later merged with Autism Speaks, to demonstrate her unique teaching methods and help other non-verbal children. Eventually, they parted ways, but Tito and Soma continued to live in the US. Tito’s prolific writing has received much critical appreciation; Savarese (2010) locates his oeuvre squarely within the neurodiversity movement, demonstrating how he pokes fun at the reigning hypotheses around autism.

The liberative possibility of his autistic identity is articulated by Tito in his ironic account of his experiences in a special education class in the US. Tito sums up the lessons he learned from the ‘humiliation’ of having his intelligence doubted.

> Humiliation also made me a scientist! I am the scientist who knows why I have autism: to experience the captivity of intellect by one’s body and to endure it with absurd aplomb, while others struggle even to fathom such captivity. As a social scientist, I know, however, that nobody is free from captivity. One is captive to one’s ego, for example, social obligations, job requirements, et cetera. Which of you neurotypicals is free to sniff a book in public? I have freedom from customary comportment, and as a sniffing scientist, I remain outside the box we term *social norms*. The rest of you purportedly free people are trapped inside the social box (Mukhopadhyaya 2015, 8).

Mukhopadhyaya represents an embodiment and politics that radically reconfigures the certitudes of the neurotypical world and its assumptions about what constitutes the normal. Savarese (2010) writes:

> By examining the work of Tito Mukhopadhyay, we can see not only evidence of a postcolonial neurology but also intimations of a very different politics. How the autistic subject understands his relationship to himself and others (both human beings and natural objects or animals) suggests are joinder to neurotypical assumptions and arrangements. That subject literally decenters and deterritorializes. Though marked by a history of exclusion and degradation, he has begun talking back to the empire of science. The subaltern has learned to speak, and he has most certainly learned to write in the master’s tongue. He is a cross-cultural, cross-sensorial migrant, a cosmopolitan armed with metaphor in a world that is often quite hostile to the neurological other (276).

The representations discussed above reveal multiple dimensions of the autism experience from the perspective of both the person with autism and their families. They hold out productive possibilities for re-imagining autistic personhood and an ethics of care, and the promise of neurodiversity in radically altering our understandings of what it means to be human. These themes are also being increasingly explored in popular cinema, albeit with far less subtlety and insight than the literary representations discussed above. In the following section, some cinematic representations of autism and other disabilities will be reviewed, to make a case for the growing salience of ‘difference’ in mainstream cinema.

Autism in Hindi Cinema

While mainstream Hindi cinema (‘Bollywood’) has always engaged with disability, these representations have generally deployed the lens of tragedy and pity. While it is fair to say that many of these portrayals are caricatures, fantastical and downright outlandish at times, they do offer insights into societal attitudes about disability and difference, and, as in the case of films like Aamir Khan’s *Taare Zameen Par* (2007), R. Balki’s *Paa* (2009), Karan Johar’s *My Name is Khan* (2010) and most recently Siddharth P. Malhotra’s *Hichki* (2018), bring to public view disabilities that are relatively unknown to viewers. The films mentioned have protagonists with dyslexia, progeria, autism and Tourette’s syndrome, and are represented in comparable ways as confounding and deeply stigmatizing conditions that profoundly challenge the ‘normative’. For the purpose of this discussion, I shall focus on ‘Bollywood’ films that reference intellectual disability and autism. These films feature popular Bollywood actors (‘heroes’ and ‘heroines’, as they are referred to in India) and deploy the cinematic language of the mainstream Hindi film that generally has a much larger audience than the more serious offerings in experimental or alternative cinema.

The infantilization and denial of normative masculinity to the intellectually disabled male discussed elsewhere (Mehrotra and Vaidya 2008) is a theme that features prominently in the fantasy drama *Koi Mil Gaya* (‘I found somebody’) (2003, dir. Rajesh Roshan) which narrates the story of Rohit, a ‘man in a child’s body’, and his relationship with Jadoo, a rather endearing alien from a distant galaxy. Rohit, framed as the eternal child by his mother, continues to study in a lower grade at school with children much younger than him. His disability, indirectly caused by aliens, is also remediated through his encounter with Jadoo, the extraterrestrial, who endows him with the physical and mental strength that is the marker of a competent masculine identity, and thus qualifies him to enter into an adult relationship with the young woman who befriends him. However, it is in the relationship between Rohit, his young friends and Jadoo that we see the possibility of an alternative way of being that is different from the worldly and instrumental discourse of normalcy. This depiction has a resonance with the parental narratives reported by Vaidya (2016: 70–71) in which the autistic child is constructed as lacking *samajhdaari* (Hindi for ‘understanding’) and therefore uncorrupted and untainted by the demands of the material world. The narrative by Srinivas (2016) in the previous section also hints at this.

Karan Johar’s *My name is Khan* (2010), with Shahrukh Khan playing the protagonist, addresses the complex issue of Islamophobia in post 9/11 America, through the story of Rizwan Khan, a man with Asperger’s syndrome. Rizwan migrates to the US after the death of his mother and builds a life in America, marrying a young Hindu woman, Mandira, and adopting her son Sameer (Sam). Sam is killed in a schoolyard hate crime, and Mandira holds Khan’s Muslim identity as the reason behind the crime. Their relationship collapses, and Khan sets off on a journey across America to meet the President face to face and convince him that though his name is Khan, he is not a terrorist. By declaring his innocence to the President of the United States, Rizwan hopes to win back the trust of his grief-stricken wife. Khan's autism is a metaphor for a mind that is unsullied by the viciousness of identity politics and believes that the only difference between human beings is their capacity to do good or evil. This 'simplicity' lands him into all kinds of trouble, even puts his life in danger, but ultimately redeems him; holding out the possibility of hope and healing in a world rent by prejudice and hatred. However, the real issue of Islamophobia in contemporary America is rather conveniently elided. Khan's narrow focus on fixing his broken domestic relationship depoliticizes the contexts of racial and ethnic profiling and prejudice, even though these are portrayed in the film through his encounters with law enforcement and security agencies. Once again, the tendency to view autism as a thing apart from the sociopolitical contexts in which it is embedded renders the narrative as a rather syrupy 'love story' in which the 'hero' ultimately regains the affections of his 'heroine'. And yet, it does bring home the possibility of a politics that is grounded in a sensibility and subjectivity that is 'different' and more humane that distinguishes between good and evil, irrespective of community identity and political affiliation.

A film in which both protagonists have a disability is *Barfi!* (2012), directed by Anurag Basu. The fairy-tale-like story of a deaf young man, Barfi, and a young autistic woman, Jhilmil, is an interesting take on how persons with severe communication challenges do manage to 'communicate' affection, friendship and caring. Their relationship assumes a particular quality of playfulness that is of a piece with their embodied differences, even though the depiction of autism in the film is simplistic and superficial, to say the least.

These films have played a role in bringing conditions like autism and intellectual disabilities into public view, albeit in a formulaic style, replete with the stereotypes that surround disability and couched in understandings of the disabled person as being somehow apart and not enmeshed in the routine, quotidian messiness of everyday life. Liberally seasoned with the 'masala' that lends Bollywood its unique flavour, they have nonetheless opened up conversations around disability and foregrounded the possibility of viewing it not as a pitiable tragedy, but a dimension of human difference and diversity.

Concluding Observations

In the above, we have looked at the development of the discussions around autism in multiple domains; from clinical research to service provision, parental advocacy, legislation and representations. What does the 'autism scenario' look like in India today? As compared to the situation two decades ago, it is clear that there is considerably more public awareness and recognition, at least in urban India. Disability has come out of the closet and has become more visible in public spaces. 'Disability stories' are being told in the media, often in tokenistic ways (e.g. special programmes and features to commemorate World Autism Awareness Day on 2 April or World Disability Day on 3 December). An ecosystem around rehabilitation and special education has also grown, and the 'helping professions' are now being seen as viable livelihoods, rather than 'social service' exclusively rendered by family members. 'Inclusion' has become a buzzword in theory, if not in practice, and mainstream schools are slowly but surely opening their doors to children with autism.

From being a virtually unknown category amongst medical professionals, autism has become an increasingly common diagnosis. A special issue of the *Indian Journal of Pediatrics* in January 2017 carried papers on early intervention, social and communication issues, educational and behavioural interventions, governmental schemes and the rights of children with autism.[11] This indicates that professionals across the medical and advocacy domains are in conversation with each other. Indigenous screening tools for autism in India (the INCLEN Diagnostic Tool and the Indian Scale of Assessment of Autism) have been developed and notified as the instruments for assessment and quantification for issuing the all-important disability certificate, which was earlier not available for persons with autism. The requirement of medical certification and expertise to enable access and equity to social-economic goods testifies the ubiquity of the medical model, an irony that has been critiqued by disability rights activists.

However, in the larger sociopolitical context, polarization and the demonization of the 'other' have become widespread. Disability is still seen as an apolitical category in India, and thus treated with a benign condescension that reflects in new terminologies like '*divyaang-jan*' (divine people) to replace the earlier term '*viklaang*'(impaired) to denote persons with disabilities. The representations discussed above demonstrate this, to some extent; the stereotype of the compliant and docile disabled person is however being challenged in academic and activist circles with the emergence and growth of disability studies in the academy and the rights movements in the public sphere.

Within the new economy, participation of persons with disability is also receiving attention. The disabled body as a source of 'value' in the new economy has been discussed by Friedner (2015), among others. Persons with autism and intellectual disabilities are also being recruited into open employment as part of CSR initiatives; however, some of the placements offered conform to stereotypes of the disabled worker as a low-value one, fit only for those dead-end tasks that a non-disabled worker may not want to do on a long-term basis.

A quarter of a century after autism made inroads in the disability landscape of India, issues of adulthood, employment and residential options have become important. There is also a qualitative shift in the envisioning of autistic futures with the possibility of independent living being a realistic and attainable goal. The activism of parents' groups two decades ago laid the foundations for creating social spaces and opportunities for persons with autism in India. Hopefully, the discourse they

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[11] The Indian Journal of Pediatrics, vol. 84, no.1, January 2011, https://link.springer.com/article/10.1007/s12098-016-2262-4, accessed on 20 December, 2017.

opened up will develop in enabling and productive ways to foster inclusion and human rights of all persons with autism. Interdisciplinary scholarship that attempts to integrate medical, social, cultural, legal, etc. perspectives to foster a holistic understanding of the manner in which individuals and communities understand and live the experience of disability is the need of the hour.

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