

# CHAPTER 1:

## INTRODUCTION

## 1.1 Concept of Disability

*‘Being deformed and paralysed, blind, or deaf - or old or mentally sick for that matter - is not a crime, or in any meaningful sense of the words, a divine punishment... We are perhaps also saying that society is itself sick if it can't face our sickness, if it does not overcome its natural fear and dislike of unpleasantness as manifested by disability.’*

- Paul Hunt, British disability activist in *‘Stigma: The Experience of Disability’* (1966)

According to 2011 Census, India had 2.68 crore persons, or 2.21% of the population who were identified as having one or more disabilities (NSSO, 2016).

Who are disabled? They get mentioned in idioms such as *‘Andho main kana raja’* (Person with one eye can be a king among the blind) or in everyday derisions like *langda* (having leg deformity). They are often used as tropes in popular media as comic relief (e.g., Tusshar Kapoor in *Golmaal* film series) on one side of the spectrum and heroes braving all odds (e.g., theoretical physicist Prof. Stephen Hawking) on the other.

In general parlance, the term disability refers to physical or psychological condition considered to have predominant medical significance (Reddy, 2016). Disability as a universal phenomenon connotes disadvantage, incapability, deficiency, especially a physical or mental impairment, that restricts normal achievements. In other words, disability may be visible or hidden, may be permanent or temporary, and may have minimal or substantial impact on a person's abilities (Reddy and Sree, 2017).

But struggle of persons with disabilities (PwDs) is not new. While societal changes and decades of activism coupled with advancing assistive technology has helped PwDs forge their distinct identity and becoming independent individuals, it is a constant endeavour to brush aside ‘the others’ tag and be part of the ‘mainstream.’

### 1.1.1 ‘The Others’ through the ages

Different ancient societies dealt with PwDs in different fashion – in her blog for the New Statesman, Victoria Brignell, a tetraplegic, mentioned that the terms used for the disabled included ‘teras’ in Greek and ‘monstrum’ in Roman – the words they also used to describe mythological monsters.

‘The birth of a disabled child was regarded by the Romans as a great misfortune. A high percentage of disabled children were abandoned outdoors immediately after birth and left to

die because many Romans felt it was pointless to prolong lives that could prove to be a practical and financial burden on the rest of the family,’ she wrote (Brignell, 2008).

In India, the scriptures have multiple examples of PwDs – ranging from Manthara in epic Ramayana, who is often depicted as a woman with hunchback, or the Kuru king Dhritarashtra in Mahabharata, who is described as a person with blindness.

The treatise of Manu (*Manu Smriti*) is often cited for the ‘Law of Karma’ responsible for the birth of a disabled. ‘Thus, in consequence of a remnant of (the guilt of former) crimes, are born idiots, dumb, blind, deaf and deformed men, who are (all) despised by the virtuous’ (Miles, 1995).

Epics like Mahabharata have multiple characters depicted as those with disabilities or those interacting with them - the tale of Savitri and Satyavan show how she got her father-in-law Dyumatvan’s eyesight back whereas on the other hand, the tale of Pradweshi depicts her as a wife to blind Dirghatamas (where the name itself means prolonged darkness) who abandons him (Thomas and Thomas, 2002). Miles (2002) also gives example of sage Ashtavakra and devout singer Surdas as positive depiction of PwDs in Indian context. Similarly, Jataka tales also have mention of alms to the disabled and other charitable practices.

Sanskrit text *Apastamba Dharmasutra*, considered to be one of the oldest Dharma-related texts in Hinduism, mentions that along with Vedic scholars, women, pre-pubescent boys, students, ascetics and personal servants, people who were ‘blind, dumb, deaf and sick’ were also excluded from taxes (Olivelle (1999).

In Buddhism, the theory of *karma* is seen as the pivotal force behind cycle of births as the present life is result of the past lives’ karma. Thus, the impairment is seen as a punishment for the evils of the past lives. In the tale of *Khujjutara*, a servant at a king’s palace, it’s mentioned that she had got birth as a hunchback as she had teased a deformed person in her previous birth (Ranta, Kumar, and Gupta, 2016).

In medieval times, majority of the mentions involving PwDs are in context of alms or charity. For example, during the reign of Sher Shah Suri (1472-1545), destitute and ‘those who were unable to provide for their own subsistence, like the blind’ were given stipends from the treasury (Miles, 2002).

Within the rhetorical framework of the seventeenth and eighteenth centuries, *deformity*, *defect*, and *monstrosity* emphasize ‘the allegorical, the aesthetic, and the moral dimensions of

impairment, each suggesting a distance from God or a threat to the body politic’ (Altschuler and Silva, 2017). While ‘deformity’ was a preferred word in the eighteenth century, different words and definitions give a peek into the prevalent ideas about mind and body.

### 1.1.2 Understanding Disability: Ideas and Definitions

Over the centuries, concept of disability has evolved depending on the social conditions, acceptability of different representations and laws. For a long time, the persons with disabilities (PwD) were identified by their disabilities – blind, handicapped, deaf-mute, lame, imbecile, and cripple to name a few.

Oxford English Dictionary terms disability (noun) as – 1. a physical or mental condition that makes it difficult for somebody to do some things that most other people can do, and 2. a physical/developmental/intellectual disability (Oxford Learner’s Dictionary, n.d.). But is it easy to define disability?

According to World Health organization (WHO), ‘Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions – An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.’ (WHO, n.d.)

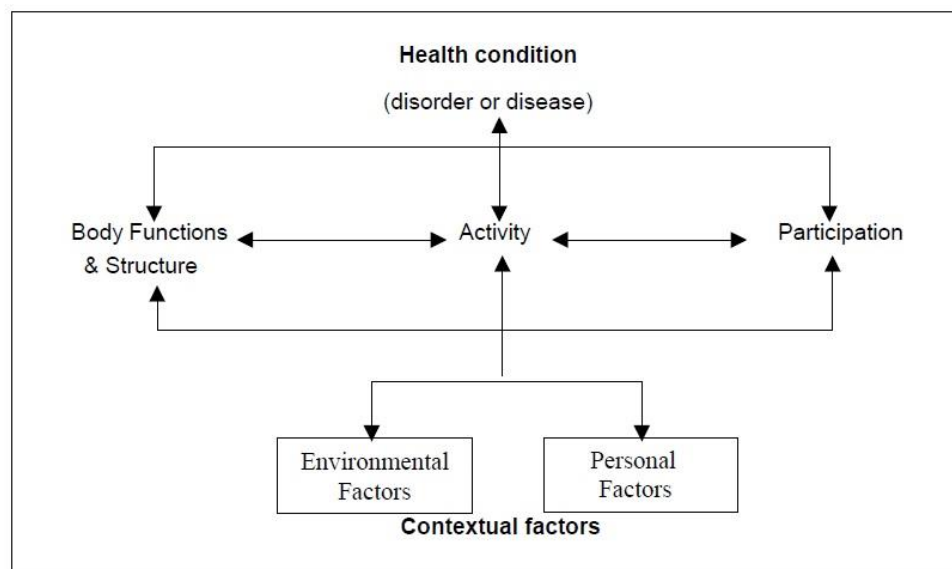


Figure 1: Disability as Interplay of Health Conditions and Contextual Factors (WHO, 2002)

The International Classification of Functioning, Disability and Health, known as ICF by World Health Organization (WHO), looks at disability in terms of interaction between health conditions (disease, disorders, and injuries) and contextual factors.

The definition also considers external environmental factors (social attitudes, architectural characteristics, legal and social structures, etc.) and internal personal factors (gender, age, social background, education, etc.) (WHO, 2002).

The definitions often try to make sense of ‘impairment’ and disability. An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment becomes a disability when the society creates environments with barriers which could be related to attitude, built-environment, cognitive or sensory (Davis, 1999). For example, a wheelchair user can access upper floors of a building if there is an elevator/ ramp available.

Article 1 of The United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD) considers those with ‘long-term physical, mental, intellectual, or sensory impairments’ as persons with disabilities (PwDs) which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (DESA, n.d.). European Union has adopted the same definition (ERA, n.d.).

An individual with a disability is defined by the Americans with Disabilities Act (ADA) as ‘a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.’ The ADA does not specifically name all the impairments that are covered (USDJ, 2020).

European Union’s Measuring Health and Disability in Europe (MHADIE)-supported policy development Consortium (2005-07) proposed the following definition: ‘Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors.’ (Leonardi et. al., 2006)

In Indian context, before introduction of the Rights of Persons with Disabilities Act, 2016, the earlier acts defined who legally is termed a PwD.

Section 2(i) of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 covered following conditions as disabled – blindness, low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation, and mental illness.

The Act also defined a PwD as a person suffering from not less than 40% of any disability as certified by medical authorities (Legislative Department, 1996).

According to Section 2(j) of The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, a PwD is a person suffering from any of the conditions relating to autism, cerebral palsy, mental retardation, or a combination of any two or more of such conditions and also multiple disabilities (MoSJE, n.d.).

### 1.1.3 Models of Disability

A model is a set of guiding assumptions, concerns, and propositions about the nature of phenomena or human experience. In context of disability studies, models provide definition of disability, shape self-identity of PwDs, provide explanations of casual and responsibility attributions and can also cause prejudice and discrimination (Smart, 2001).

Different authors have given different models to understand disability. Understanding of disability has come a long way from it to be an act of God to a socially constructed phenomenon and idea of an identity. Here are a few major models –

- **Moral/ religious model**

The oldest belief about disability found in several religions is the condition to be an act of God because of sins by a person. Researchers point out that some forms of Bible interpretations equate various disabilities with ‘human sin, evil or spiritual ineptitude’ (Retief and Letšosa, 2018).

Niemann (2005) highlights the negative influence of the moral and/or religious model of disability on theological reflection: ‘Whether congenital or acquired, many theologies have historically constructed disabilities to be a curse, one often associated with the attribution of shame onto an individual or family’. In Asian religions, primarily Hinduism and Buddhism, disability is seen as result of ‘karma’ or deeds of the past birth which gets manifested as deformity and disability for persons.

- **Medical model**

The most prevalent and influential of the concepts related to disability looks it as a medical problem that resides in the individual. As Olkin (2001) points out, disability is seen as ‘a defect in or failure of a bodily system and as such is inherently abnormal and pathological.’ The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment). The model implies that the PwDs are different from the ‘normal’ persons.

This model considers disability as a pitiable condition or a personal tragedy – for both individual and family – to be prevented and if possible cured (Carlson, 2009).

The ‘sick role’ projected on PwDs fails to recognize distinction between impairment and sickness (Llewellyn, Agu, and Mercer, 2008) as ‘many people are not sick, but have ongoing impairments.’

Several scholars and activists such as Linton (1998) criticized the model based on its medicalization of disability that considers human variation as ‘deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy.’

#### ▪ **Social model**

With advent of assistive technology and rebellion against conventional medical model, the social model of disability was propagated in 1960s and 70s by groups such as Union of the Physically Impaired Against Segregation (UPIAS) in the UK which emphasized the role of society in defining disability instead of seeing it as a personal tragedy.

In the past 50 years, it is the most widely acceptable and influential way in which disability is seen as a social construct. Unlike the earlier beliefs, the social model broke the causal link between impairment and disability – the impairments are not seen as the reason for a PwD’s economic and social disadvantage (Oliver and Barnes, 2010). Instead, the focus shifted on how the society restricts their entry into mainstream activities. Thus, the model argued that any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation (Barnes, Mercer, and Shakespeare, 2010).

The model primarily differentiates between concepts of ‘impairment’ and ‘disability.’ While the former refers to ‘lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body,’ the latter signifies ‘disadvantage or restriction of activity caused by contemporary social organization which takes no or little account of people who have physical impairments’ (UPIAS, 1976).

Social model of disability is widely accepted across the globe, prompting various governments and international bodies to formulate policies. However, it is not free of criticism. Giddens (2006) points that the model seemingly ignores realities of impairment – We are not just disabled people, we are also people with impairments, and to pretend otherwise is to ignore a major part of our biographies.’

Attempts have also been made for hybrid models (Beaudry, 2016) or different approaches towards existing theories (Smeltzer, 2007) that bridges the concerns of an impairment and societal approach towards it but scholars are yet to formulate a widely-accepted model of disability.

#### ▪ **Other Models**

Retief and Letšosa (2018) also list out *Identity model* (disability as a certain type of experience in the world which is not designed with disabled persons in mind), *Human rights model* (emphasizing on dignity of the PwDs and demand for social justice mechanism), *Cultural model* (stressing on how culture is forced through institutions or ‘manufactured locations’), *Charity model* (seeing PwDs as victims of their impairment and nudging 'able-bodied' members of the society to assist them in whatever way possible), and *Economic model* (looking at disabling effect of impairment on a person's labour and employment capabilities) as some other lenses to see and understand disability in societal context.

Smart and Smart (2011) divide the models into biomedical, socio-political, functional and environmental models, adding that attributions have the power to ‘individualize and privatize the experience of disability by looking for (and seemingly finding) both the cause and solution for the disability wholly within the individual rather than within the social system.’ The models, theorizing the phenomenon, often takes defining role and also affects the policies and services (Smart and Smart, 2011).

#### ▪ **Concept of ableism**

Campbell (2009) defines ableism as –

*a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical, and therefore essential and fully human. Disability then is cast as a diminished state of being human. (p.5)*

As a concept, ableism takes the opposite stance than disablism that focuses on negative aspect of disability. In the ‘us’ versus ‘they’ debate, ableism characterises impairment or disability as inherently negative which should be ameliorated, cured, or eliminated (Campbell, 2009). It continues the age-old bias against the ‘other’ – PwDs – who are seen as aberrations instead of an integral part of a diverse society. (Hehir, 2007, Wolbring, 2008)



The concept of identity politics is also closely related with this idea. Another concept often criticized in disability studies is social Darwinism that believes that humans are also subject to the same law of ‘survival of the fittest’ which is applied to the plants and animals in nature.

#### 1.1.4 Disability rights campaigns in the past 50 years

Disability studies can trace its origins to the organizations of persons with disabilities (PwDs) whose voices emerged in the late 1960s and who shared ideas drawn from those of other previously excluded groups such as persons of colour, ethnic minorities, sexual minorities and so on. Disability activities in the US, the UK, Scandinavia, and other Western European countries campaigned for a change in the way that disability was understood, demanding the redefinition of disability from a personal, medical problem to a political one (Driedger 1991).

No longer, they argued, should disability be seen as a problem of the individual’s ‘body’ and something to be treated by health and social care professionals, but as a political and socially constructed problem where persons with impairments face disabling barriers (De Jong 1981, Finkelstein 1980). The core demand however was rights of equal participation as they contested their incarceration in institutions and highlighted discrimination they faced in daily lives (Sabatello, 2018).

Thus, ahead of the Convention on the Rights of Persons with Disabilities (CRPD) by the UN in 2006, the theme of International Day of Disabled Persons in 2004 was ‘Nothing about Us, Without Us’ (United Nations, 2004) that became a rallying cry across the globe.

In the US, Ed Roberts in Berkeley and Judy Heumann in New York city started movements for rights of the PwDs. Roberts, a quadriplegic and wheelchair user, had to live in the university health facility along with several other students with disabilities due to lack of accessible housing on the campus. These students initiated a programme on Berkeley campus to provide support to the peers. Likewise, in 1970, Heumann - a paraplegic and a Long Island University graduate - filed a lawsuit when she was denied teaching certificate due to her disability (Scotch, 2016). In 1974, the American Coalition of Citizens with Disabilities (ACCD) was formed.

In the UK during this time, the activists such as Paul Hunt and Vic Finkelstein led a movement that gave birth to the concept of ‘social model of disability.’ In 1972, Hunt along with others established the Union of Physically Impaired Against Segregation (UPIAS) that influenced the thought. The model asserted that disability is not caused by a person’s impairment but by structural or attitudinal barriers that these persons face (Brittain and Beacom, 2018).

In 1975, the UN produced a special charter for persons with disabilities (PwDs) and their human rights. While it had no enforcement powers, it recognized disability as a rights-based issue and not an impairment issue (Hurst, 1998). In 1976, the UN General Assembly passed a resolution to mark the year 1981 as International Year of Disabled Persons with focal theme ‘full participation and equality’ to encourage rehabilitation of 450 million persons having some form of physical or mental impairment (Mehta, 1983).

However, in 1980 a World Health Organization (WHO) classification defined disability as a functional limitation of the individual, attracting ire of the activists.

The US introduced The Americans with Disabilities Act (ADA) in 1990. The Act focused on four key areas of employment protection; access to public services; accessibility and non-discrimination in public places including hotels, restaurants, hospitals, etc.; and in services offered by private entities including relay services available to the speech and hearing impaired persons (Prince, 2010).

Two years later, Australia introduced Disability Discrimination Act (DDA). The UK passed DDA in 1995.

In the late 1990s-early 2000s, a new disability model was developed in Scandinavian countries, which is identified as the (Nordic) Relational Model of Disability. The model has three primary guiding principles – disability is a person-environment mismatch, it is contextual and relative (Jackson, 2018).

### **UN Convention on Rights of Persons with Disabilities (UNCRPD)**

In 2006, the UN introduced the Convention on Rights of Persons with Disabilities (CRPD) as ‘the first comprehensive human rights treaty of the 21st century’ (United Nations, n.d.). The convention came into force in May 2008 and influenced laws and policies of many countries including India.

The eight guiding principles of CRPD included –

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society

4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

### **Sustainable Development Goals (SDGs)**

The sustainable development goals (SDGs) set by the UN Conference on Sustainable Development, which were to be achieved by 2015, are now extended till 2030 with its integration in the United Nations global development agenda.

Disability is included in the following five of the 17 goals (United Nations, 2019)

**Goal 4 | Quality Education:** Guaranteeing equal and accessible education by building inclusive learning environments and providing the needed assistance for persons with disabilities

**Goal 8 | Decent Work and Economic Growth:** Promoting inclusive economic growth, full and productive employment allowing persons with disabilities to fully access the job market

**Goal 10 | Reduced Inequalities:** Emphasizing the social, economic, and political inclusion of persons with disabilities

**Goal 11 | Sustainable Cities and Communities:** Creating accessible cities and water resources, affordable, accessible, and sustainable transport systems, providing universal access to safe, inclusive, accessible, and green public spaces

**Goal 17 | Partnerships for the Goals:** Underlining the importance of data collection and monitoring of the SDGs, emphasis on disability disaggregated data

### **Indian movements and activism**

In the backdrop of international movements, disability rights activism took place since early 1990s in India. However, it remained fragmented compared to other movements, possibly because 'PwDs were and are a divided group signified by diversity.' Disability cuts across race,

caste and class divisions and thus likelihood of framing groups was not a simple possibility (Mehrotra, 2015).

Mehrotra added in her piece in The Economic and Political Weekly (EPW) that more than 70% of the disabled live in rural areas where getting information related to disability rights was not easy. *‘The attitude of the Indian state was clearly informed by the medical, charity and religious model where PWD were construed as dependents and beneficiaries of state provisions... The theory of karma, family ideologies, attitudes of charity and pity marked the attitudes of society towards the PWD and clearly informed state policies towards them,’* she wrote (ibid.).

One can also look at the international events such as the Decade of Disabled Persons (1983-92) and pressure from global agencies that led to the passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, in India in 1995.

Meenu Bhambhani, a woman with disabilities, completed her PhD on theme of ‘From Charity to Self-advocacy: The emergence of disability rights movement in India.’ According to her thesis, the Disability movement in India is a post-legislative phenomenon unlike other countries like the US where the movement culminated in the passage of Americans with Disabilities Act (Bhambhani, 2018).

She argued that according to many scholars there was no ‘disability movement’ in South Asia including India, as it was more of a western-centric approach of struggles initiated by disability activists. She counterbalanced it by highlighting that India witnessed aggressive campaigns from 2000 to 2004 for creating awareness about the law (PwD Act, 1996) and advocating basic machinery to enforce act’s provisions.

Anita Ghai, a woman with disabilities and disability scholar, point out the gender and socio-economic angle of the disability movements in India. She wrote in ‘Disability and Social Movements: A Reflection’ that as an activist and academician, she has felt the disability movements are not focused on feminine concerns such as reproductive health and violation of the basic rights.

*‘In the fights for visibility in society, inclusion in the census, discounted rates in hotels, and other such contexts, one can clearly see the middle-class, male-centric concerns that are guiding the development of the disability groups,’* she wrote (Ghai, 2015).

Mehrotra (2012) notes that in the recent past, the assertion of rights groups along with national and international policies have made disability visible in Indian context. In NGOs and metropolitan universities, efforts are on to underline the importance of disability issues in social science understandings.

## 1.2. Role of Media in Representation of Disabilities

According to the UN's Department of Economic and Social Affairs (DESA), media can be a vital instrument in raising awareness, countering stigma and misinformation. It can be a powerful force to change societal misconceptions and present persons with disabilities as individuals that are a part of human diversity. (DESA, n.d.)

*'Attention should be drawn to the image of disability in the media with a view to an accurate and balanced portrayal of disability as a part of everyday life. The media can play an important role in presenting disability issues in a way that could dispel negative stereotypes and promote the rights and dignity of persons with disabilities.'* (ibid.)

Media is a core way to encounter disability and a key way in which it is shaped and governed in society. Social forces change media, but in return, media powerfully influences society, especially in the realm of disability (Ellis and Goggin, 2015).

PwDs have identified ten commonly recurring disabling stereotypes in the mass media. These include: the disabled person as pitiable and pathetic, as an object of curiosity or violence, as sinister or evil, as the super cripple (supercrip), as atmosphere, as laughable, as her/his own worst enemy, as a burden, as non-sexual, and as being unable to participate in daily life. These stereotypes are particularly evident on television, in the press, and in advertising (Wood, 2012).

### 1.2.1 Portrayal of PwD in Films and Television

Newspapers, television, and movie coverage regarding disability has traditionally conveyed more misinformation and stereotypes than accurate information (Black and Pretes, 2007) News stories about disability are typically human-interest stories that depict persons with disabilities as victims of some tragedy or conversely stories of courage in which the individual with the disability has accomplished something 'in spite of' the disability.

Hindi films especially have used several disabilities as narrative trope in films such as Dosti (1964), Koshish (1972), Sadma (1983), Khamoshi (1996), Black (2005), Iqbal (2005), Taare Zamin Par (2007), Guzaarish (2010), Lafangey Parindey (2010) My Name is Khan (2010) and

more recently in Barfi! (2012), Margarita with a Straw (2015) and Kaabil (2017) to name a few.

But lasting image of how disability is seen as a punishment is exemplified by Thakur's amputation by dacoit Gabbar in 1975 blockbuster 'Sholay' and similar punishment dished out to Gabbar by Thakur in the end (Pal, 2013). Several other examples could be found in films such as Koshish, Aadmi and so on – where theme of 'such a life is worse than a death' echoes through the narrative. Pal notes that disablement of a character is also presented in Hindi films such as Upkaar and Kaalia to motivate the protagonists.

Several Hollywood films and American TV and web series also depict persons with disabilities as protagonists or primary characters such as Rain Man (1988), Scent of a Woman (1992), The Miracle Worker (2000), I am Sam (2001), Music Within (2007), Quid Pro Quo (2008), Me Before You (2016), Netflix's Daredevil (2015) and so on.

Avatar (2009), one of the highest-grossing films of all-time, is often seen as a disability film with protagonist Jake Sully's paraplegia represents a primary cog in the movie's narrative mechanics (Wetherbee, 2015). Even in Marvel Cinematic Universe (MCU) franchise, characters such as Makkari (in Eternals, 2021) and Echo and Hawkeye (in Hawkeye, 2021) are portrayed with disabilities. In the comics and movies, the X-men leader Prof Charles Xavier is portrayed as a person with paraplegia using wheelchair.

Popular TV show 'Game of Thrones' is one example where the narrative speaks to the broader notions of social disablement (Ellis, 2014). Ellis cites David Radcliff from 'Winter is Coming' stating, *'Since its earliest episodes, (Game of Thrones) has introduced us to a paralyzed boy with a supernatural gift, has endeared us to a Little Person defined not by his height but by his wit, and has regularly mined the lives of "cripples, bastards, and broken things" to celebrate their strengths and complexities.'* (ibid.)



Figure 2: Disability representation in popular media – Row 1: Becky from Glee, Boji from Ranking of Kings, Professor Charles Xavier from X-Men; Row 2: Sir Hammerlock from Borderlands, Shoko Nishimiya from A Silent Voice, First issue of Capable; Row 3: Clint Barton from Hawkeye, Makkari from Eternals, Dr Shaun Murphy from the Good Doctor

An article in The New York Times by Bahr (2022) lauded the Oscar win for Troy Kotsur as the first person with hearing impairment to win the award (best supporting actor) for movie Coda, portrayal of Makkari by Lauren Ridloff, an actor with speech and hearing impairment, and ‘silent’ episodes of ‘Only Murders in the Building’ series to provide perspective of a character with hearing impairment. The Nielsen database indicated that out of 1.64 lakh films and TV Shows from 1918, only 6,895 had significant disability themes or content.



### 1.2.2 Terminology

The terminology used to refer to persons with disability may both reflect and influence attitudes towards them. Negative references may perpetuate negative attitudes and stereotypes. This is of particular importance in the mass media which reaches a broad spectrum of the population.

Studies such as Gold and Auslander (1999) highlighted that the disability terminology used in major newspapers in Canada and Israel was not appropriate most of the times and the choice cannot be explained by journalistic expedience and conciseness alone.

Activists even reject the ‘special,’ ‘differently-abled’ and ‘physically challenged’ tags (Linton, 1998), saying that they are part of social construct that puts onus on the individual instead of the social or cultural barriers.

While there are not set guidelines for press to use or not use words related to disability, International Labour Organization (ILO) had issued guidelines about reporting on disabilities. The publication ‘Reporting on Disability: Guidelines for the Media’ asks reporters to use better alternatives which can represent the person and sector better – insisting that disability is not synonymous with suffering (ILO, 2015). A few examples:

*Table 1: ILO Guideline on Disability Terminology*

<b>Avoid phrases like</b>	<b>Use phrases like</b>
Birth defects, deformity	Person born with a disability
Confined to a wheelchair	Person who uses a wheelchair
Insane, psychotic, lunatic, schizophrenic	Person with a mental health disability
Differently-abled	Person with a disability
Handicapped washrooms, parking	Accessible washrooms, parking

### 1.3. A brief history of disability in India and legal framework

In India, the earliest act dealing with PwDs was the Indian Lunacy Act, 1912, which was later replaced by the Mental Health Act of 1987.

Mehta (1983) noted that in first three Five-Year plans of India, there was no separate allocation for the persons with disabilities. In the fourth plan (1969-74), the budget allocated for ‘welfare of the physically handicapped’ was Rs 2.5 crore which rose to Rs 11.25 crore and Rs 25 crore in the fifth and sixth plans respectively.

#### **Counting PwDs**



According to National Sample Survey (NSS) 1973-74, the number of persons with disabilities per 1000 were

*Table 2: PwDs in NSS 1973-74*

<b>Disability</b>	<b>Urban</b>	<b>Rural</b>
Blind	0.51	1.44
Deaf	0.42	0.93
Dumb	0.31	0.68
Lame	0.48	1.07
Crippled	0.76	1.19
<b>Total</b>	<b>2.33</b>	<b>4.93</b>

*(Persons in more than disabilities have been calculated as one as the sum is bigger than total of each heads, heads kept as per the original format, Source: (Mehta, 1983)*

However, historic data on disability in India has been a major issue. While the PwDs, then identified as ‘*infirm*’ have been included in pre-independence data collection since 1872 Census, the official remark on 1931 Census said that the data on infirmity is never satisfactory. After 1931, the country witnessed gap of 50 years before disability could be counted again in 1981 Census – primarily to commemorate the International Year of the Disabled announced by the UN in the same year (Reddy and Sree, 2017). The Census had three broad categories of totally blind, totally dumb, and totally crippled.

Experts pointed at the discrepancies in data owing to different definitions of disability and stigma attached to the disability due to which data collection was not effective (ibid). Even in 1991 Census, the question on disability was dropped due to questions on reliability of data and definitions. With movements and representations by the disability rights activists, the question on disability again found place in 2001 Census. The methodology again got an update in 2011 when the enumerators were trained specifically on how to gather data on PwDs. The Census also added a category of ‘any other’ apart from conventional categories to improve data collection.

In a decade from 2001 to 2011, India witnessed a rise of 22.4% PwDs where urban areas recorded a rise of 48.2%.

Out of 121 crore population of India, the PwDs form 2.21% with presence of 2.68 crore.

*Table 3: Population of PwDs by residence and gender (Census 2001 and 2011)*

Residence	Census 2001			Census 2011			Decadal Growth		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Urban	31,95,450	23,22,937	55,18,387	45,78,034	36,00,602	81,78,636	43.3%	55%	48.2%
Rural	94,10,185	69,78,197	1,63,88,382	1,04,08,168	82,23,753	1,86,31,921	10.6%	17.8%	13.7%
Total	1,26,05,635	93,01,134	2,19,06,769	1,49,86,202	1,18,24,355	2,68,10,557	18.9%	27.1%	22.4%

The national markers of disability are also collected by National Sample Survey (NSS). The 76<sup>th</sup> round of enumeration (July-December 2018), declared in November 2019, considered 1,06,894 respondents (74,946 in rural and 31,948 in urban areas). Major findings reveal presence of disability in the country at 2.2%, prevalence of disability among male population at 2.4% compared to 1.9% among females, prevalence of disability at 86 per 1 lakh population and literacy rate at 52.2%.

The survey also revealed that only 21.8% received aid/ help from the government as only 28.8% had disability certificate. Against labour force participation of general population at 49.8%, the share of PwDs was 23.8%.

Experts such as Jeffrey and Singal (2008) have pointed out shortcomings of the methods employed in both Census and NSS when it comes to counting persons with disabilities and advocated more robust and reliable system.

### **Legal reforms**

In 1990s, international movements and conventions resulted into three acts – Rehabilitation Council of India Act, 1992, Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (Addlakha and Mandal, 2009).

Before the PwD Act of 1995, the legal cases for the disability rights were largely filed under the provisions of Articles 14 (Right to Equality) and 21 (Right to Life) of the Indian Constitution. The legislative domains such as marriage/ divorce, adoption, property, and criminology depended on healthcare aspect of disability.

As the UN passed CRPD in 2006, India became one of the first countries to ratify the Convention in March 2007. The Convention asked the state parties to implement provisions of

the Convention, harmonize country laws with the Convention, and preparation of a country report. India submitted its first country report in November 2015.

In 2006, India also introduced the National Policy for Persons with Disabilities focusing on both prevention of disabilities and rehabilitation of PwDs.

But disability remained a specialized field associated with medical science, social welfare, or charity. Even the development responses have largely remained confined to families, to a limited extent to communities, and most prominently to specialized institutions (Sonpal and Kumar, 2012).

India became a party to Incheon Strategy (2012). The international meet in South Korea was to review the implementation of the Asian and Pacific Decade of Disabled Persons, 2003-2012. The members were part of the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP). The strategy underlined the need for 'To make the right real' and passed the resolution in May 2013.

India was part of the working group till 2022 to work towards the rights of PwDs and is also a signatory to Beijing Declaration in 2017 that outlined the plan to achieve goals of Incheon Strategy in five years.

The Rights of Persons with Disabilities Act, 2016 was enacted on December 28, 2016 and came into force from April 19, 2017. The Department of Empowerment of Persons with Disabilities (Divyangjan) at the Ministry of Social Justice and Empowerment (MoSJE) oversees implementation of the Act along with The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, and Rehabilitation Council of India Act, 1992.

According to the Ministry website (MoSJE, n.d.), salient features of the Act include,

- i. Responsibility has been cast upon the appropriate governments to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others
- ii. Disability has been defined based on an evolving and dynamic concept
- iii. The Act covers the following specified disabilities-
  1. Physical Disability

- a. Locomotor Disability
    - i. Leprosy Cured Person
    - ii. Cerebral Palsy
    - iii. Dwarfism
    - iv. Muscular Dystrophy
    - v. Acid Attack Victims
  - b. Visual Impairment
    - i. Blindness
    - ii. Low Vision
  - c. Hearing Impairment
    - i. Deaf
    - ii. Hard of Hearing
  - d. Speech and Language Disability
2. Intellectual Disability
- a. Specific Learning Disabilities
  - b. Autism Spectrum Disorder
3. Mental Behaviour (Mental Illness)
4. Disability caused due to-
- a. Chronic Neurological Conditions such as-
    - i. Multiple Sclerosis
    - ii. Parkinson's Disease
  - b. Blood Disorder-
    - i. Haemophilia
    - ii. Thalassemia

iii. Sickle Cell Disease

5. Multiple Disabilities

- iv. Additional benefits have been provided for persons with benchmark disabilities and those with high support needs
- v. Every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education
- vi. 5% reservation in seats in Government and Government aided higher educational institutions for persons with benchmark disabilities
- vii. Stress has been given to ensure accessibility in public buildings (both Government and private) in a prescribed time-frame
- viii. 4% reservation in Government jobs for certain persons or class of persons with benchmark disability
- ix. The Act provides for grant of guardianship by District Court or any authority designated by the State Government under which there will be joint decision – making between the guardian and the persons with disabilities
- x. Broad based Central and State Advisory Boards on Disability to be set up as policy making bodies
- xi. The Act provides for strengthening of the Office of Chief Commissioner of Persons with Disabilities and State Commissioners of Disabilities which will act as regulatory bodies and Grievance Redressal agencies and also monitor implementation of the Act. These Offices will be assisted by an Advisory Committee comprising of experts in various disabilities
- xii. Creation of National and State Fund to provide financial support to the persons with disabilities
- xiii. The Act provides for penalties for offences committed against persons with disabilities
- xiv. Designated special Courts to handle cases concerning violation of rights of PwDs

A year before the Rights of PwD Act, 2016, Government of India had launched *Sugamya Bharat Abhiyan* (Accessible India Campaign) on December 3, 2015 - International Day of

Persons with Disabilities. According to the official website of the initiative, it was launched as ‘a nation-wide campaign for achieving universal accessibility for PwDs.’ (MoSJE, n.d.)

The three primary components of the initiative include - Built environment accessibility, Transport system accessibility, and Information and Communication Technology (ICT) ecosystem accessibility.

The campaign also had its share of criticism. Experts pointed out that the focus of the initiative was largely urban, retrofitting the existing infrastructure and the ‘accessibility’ standards in terms of minimum requirement and design were unclear (Gupta, 2016).

## 1.4. Statement of the Problem

The Rights of Persons with Disabilities Act, 2016 along with Accessible India and the word ‘Divyang’ in 2015 changed the way the central and state governments and society at large view disabilities and persons with disabilities (PwDs) by shifting focus of activities from charity to rights. The Act also makes provisions for inclusivity and equal opportunities. However, mere legal provisions would not automatically change the societal approach towards the issues of persons with disabilities (PwDs) – media as an integral part of a democratic society plays a vital role in the process. Media – both print and electronic – are often criticized for stereotyping the PwDs and showing them in a specific light. The holistic depiction not only highlights their issues but also helps build public opinion on the subject that in turn impacts their social participation from employment opportunities to marriages.

Thus, the present study proposes to investigate changes in coverage of/approach towards the disability-related issues in mainstream media in the state of Gujarat in the light of the three factors mentioned above. The study also aims to record changes in terms used for PwDs and perception of PwDs about their representation by media.

## 1.5. Conceptual Framework

The present section provides an idea of the theories based on which the framework of the study rests. The ideas are further expanded in Chapter 3.

**Social model of disability and beyond** – Among the various models of disability devised over the years, Social Model of Disability has remained an influential one to understand disability and social integration. The model, which originated from the British disability rights campaigns in 1970s, emphasizes that the disability is a social construct, and it can be overcome with right

aids – be it in terms of accessibility, disabled-friendly built environment, technology or even the attitude of the society at large.

Forty years on, the model has faced several updates and criticisms (Shakespeare (2006), Iacovou (2020)) including terminology, approach and even its role as ‘barrier to the progress.’ However, experts agree that the model laid foundation of the future work.

Media’s role in context of the model is explained by scholars like Ellis and Goggin (2015) where they argued that disability's cultural work of negotiating difference and enforcing normalcy involves the media as a vitally important area.

**Agenda Setting Theory of Mass Communication** – Since the initial studies by Maxwell McCombs, Donald Shaw, and David Weaver in the 1970s on presidential election reporting, the Agenda Setting Theory gained ground. Agenda Setting details how media coverage affects both what the public thinks about and how the public thinks about it (Shaw, Weaver and McCombs, 1997). The theory also describes how news media influences importance placed on a specific issue of the public agenda. In context of the present study, the theory would be examined to see how coverage of disability-related issues have shaped the public imagery of the disabled population, and how weightage to disability-related issues is perceived by the PwDs and disability sector at large.

Agenda Setting is a theory about the transfer of salience from the mass media's pictures of the world to those in our heads (McCombs and Ghanem, 2001).

**Media Framing** – Erving Goffman, American sociologist in his book ‘Frame Analysis: An Essay on the Organization of Experience’ (1974) introduced the concept of framing that indicated that the frame (the way in which a specific information is represented) influences the choices by people on how to process the information. ‘Frames are abstractions that work to organize or structure message meaning,’ he mentioned.

Framing could take place through metaphor, stories, tradition, slogan/ catchphrase, artifacts, contrast, or spin (Fairhurst, 2005). Framing could both be natural and social, and it is a key part in agenda setting theory of mass media. Entman (1993) defined frames as ‘call attention to some aspects of reality while obscuring the elements, which might lead audiences to have different reactions.’

In context of the present study, framing refers to coverage of disability issues – persons with disabilities, achievements, grievances, inspirational stories, etc. by the mainstream media through both words and images.

While the study's focus is not on media for development, it touches upon the contours of development communication to examine role of media for societal change and reflecting upon societal changes.

Development communication is the process of intervening in a systematic or strategic manner with either media (print, radio, telephony, video, and the internet) or education (training, literacy, schooling) for the purpose of positive social change. The change could be economic, personal, as in spiritual, social, cultural, or political (McPhail, 2009).

## 1.6. Objectives of the Study

1. To examine and quantify print media coverage of the disability sector for the years 2015, 2016, and 2017 in Gujarat
2. To study the difference between pre-Act and post-Act (RPwD Act) coverage of disability issues in Gujarat-based newspapers including terminology
3. To find perception of the PwDs and other stakeholders on the depiction of PwD in mainstream media
4. To examine how the PwDs consume media and use of new technology for the same
5. To identify key issues related to the representation of disability sector and PwD in mainstream media

## 1.7. Research Questions

1. What has been the change in coverage of disability issues by mainstream media in Gujarat after the implementation of the Rights of Persons with Disabilities Act, 2016?
2. How PwDs in Gujarat perceive the media coverage of disability issues vis-à-vis factors such as nature of disability and education? Has technology and social media changed the way PwDs interact with media?
3. What are the factors that determine coverage of disability-related issues in media?

## 1.8. Definition of Terms

**MoSJE** – The Ministry of Social Justice and Empowerment of the Government of India. The ministry looks after the Department of Empowerment of Persons with Disabilities



**PwD** – Persons with disabilities as defined by the international conventions and The Rights of Persons with Disabilities Act

**Divyang** – The word coined by Prime Minister Narendra Modi in December 2015 literally translated to ‘Divine body/ limb’ to replace other words to describe persons with disabilities

**The RPwD Act** – The Rights of Persons with Disabilities Act, 2016

**Mainstream media** – Widely available media outlets including newspapers, TV channels and internet websites which can be accessed by all

## 1.9. Research Methodology

For the objectives of the study – examining print media coverage from 2015 to 2017, pre- and post-Act coverage of disability, perception of PwDs about coverage, consumption of media, and key issues related to disability sector in mainstream media – methods of document analysis, questionnaire and perception scale, and in-depth interview were employed. The design involving both qualitative and quantitative methods ensured that the subject of disability representation was seen from all possible angles.

The tools included document analysis of two major newspapers – one each from English and Gujarati, questionnaire administered to the PwDs and their relatives, and interview schedule for the subject experts including journalists, NGO representatives, educators/ field experts, and achievers/ award winners.

The analysis and presentation included descriptive statistics, perception scale and other statistical tools, and thematic analysis for different tools.

## 1.10. Significance of the Study

- The study documents the coverage of disability issues including frequency and most common themes related to Gujarat for the years chosen for study. It puts the issues related to disability sector and its coverage in perspective to understand why some issues get coverage when others do not.
- The study explores terminology used for the disability sector before and after the major movements and introduction of a new word in ‘Divyang’ to describe PwDs. It is one of the first studies to understand the usage of terminology by mainstream media after the word is coined.

- The study aimed to understand the media consumption pattern of PwDs in the light of new media/ social media and what media they choose to get disability sector-related news or updates. It also measured the perception of PwDs vis-à-vis disability related issues such as usage of terminology, frequency of coverage, coverage on special days, understanding of journalists and so on. The findings would help government agencies, NGOs, and policymakers to choose the right medium to reach out to the PwD community.
- The disability sector has been given impetus by the current governments in Centre and Gujarat in terms of their inclusivity in mainstream and rights-based activities. Media plays a major role in creating awareness about these issues and inputs from the subject experts covered in the present study provides an insider view on media-disability sector relationship. The outcome is timely to understand the areas that need attention in terms of communication strategy.

### 1.11. Delimitation of the Study

The study takes into consideration three years (2015, 2016 and 2017) for purpose of analysis and understanding impact of a law (The Rights of Persons with Disabilities Act, 2016) along with Accessible India initiative and ‘Divyang’ word on mainstream media. The media analysis included one newspaper each in English and Gujarati languages published from Gujarat. The questionnaire along with perception scale was administered to PwDs and their relatives who were primarily associated with NGOs based in Ahmedabad.

### 1.12. Organization of the Study

How the study and chapters are organized

Chapter 1: Introduction

1.1 Concept of disability over the decades

1.2 Role of media in representation of disabilities

1.3 Brief history of disability in India and legal framework

1.4 Statement of the problem

1.5 Conceptual framework

1.6 Objectives of the study

1.7 Research questions

1.8 Definition of terms

1.9 Research methodology

1.10 Significance of the study

1.11 Delimitation of the study

1.12 Organization of the study

Chapter 2: Review of Literature

2.1 Theories of media representation and role of media in shaping social reality

2.2 Representation of persons with disabilities

2.3 Major studies in the field of media representation of disability

2.4 Summary of review

2.5 Research gap and conclusion

Chapter 3: Research Methodology

3.1 Theoretical framework

3.2 Research methodology

3.3 Plan for analysis and interpretation

3.4 Delimitation

Chapter 4: Data Analysis and Interpretation

4.1 Document analysis

4.2 Questionnaire and Perception Scale

4.3 In-depth interviews

4.4 Converging themes

Chapter 5: Conclusion and Recommendations

5.1 Summary of findings

5.2 Conclusion

5.3 Discussion

5.4 Recommendations

5.5 Limitations

5.6 Suggestions for future research

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