India and Intellectual Disability
An Intersectional Comparison of Disability Rights Law and Real Needs

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Thesis submitted to the University of Ottawa
in partial Fulfillment of the requirements for the
Master of Arts Degree in Globalization and International Development

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Because this study includes human subject research, permission to proceed was sought from the University of Ottawa’s Research Ethics Board (REB). The application was received by the REB and approval to conduct the research was granted on 24 June 2019 (see Appendix A).

For my brother Richard and my father Howard, without whose encouragement and advice this thesis would not have been possible.

Abstract

Given its vast population, India has one of the highest absolute numbers of people with intellectual disability (PwIDs) in the world. Studies have placed the prevalence as high as 3.1% of children aged between 2 to 5 years and 5.2% of children aged between 6 to 9 years. India recently passed the Rights of Persons with Disabilities Act, 2016 (RPwD Act), to align itself with the United Nations Convention on the Rights of Persons with Disabilities. This thesis applied the complementary methods of the review of academic and grey literature, document analysis of the RPwD Act, and in-depth informant interviews to become the first full study on the extent to which the RPwD Act meets the needs of PwIDs. Drawing on the biopsychosocial model of disability and intersectional theory, the findings show that the RPwD Act only partially meets the needs of PwIDs. The RPwD Act does incorporate progressive elements such as affirmative action provisions in the labour market, measures to prevent unethical research on PwIDs, and steps toward inclusive education. However, the Act stipulates a disability certification process that remains mired in the medical model of disability and is mostly inaccessible in rural areas. It also continues the system of legal guardianship dating to the colonial era which deprives many PwIDs of legal capacity and leaves some of them confined to long-term institutions with highly inadequate levels of care. Other problems in the Act include inadequate provisions to provide privacy, reproductive rights and education, and protection from discrimination.

Keywords: intellectual disability, disability rights, disability legislation, legal capacity, inclusive education, intersectionality, India

Acknowledgements

This thesis could not have reached its present form without the dedication, support, and advice of my supervisor Paul Mkandawire. Also invaluable have been the feedback and encouragement of the other two members of my thesis committee, Lauchlan Munro and Stephen Baranyi. All three committee members have helped orient and shape the thesis throughout the long writing process and thereby saved me countless hours.

I am deeply indebted to the many wonderful researchers and representatives of Organizations for People with Disabilities, all dedicated to improving the wellbeing of people with intellectual disability, who so generously discussed the issues explored in this thesis in interviews with me. Each has made a very important contribution. Likewise, I could not have finished without the help of several people who graciously took the time to connect me with interview subjects.

Lastly, my family's support has been indispensable throughout the writing process. Thank you to my brothers Richard and Billy, my mother Sharon, and my father Howard, all of who have contributed in important and essential ways.

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List of Abbreviations

ASDs	autism spectrum disorders
BJP	Bharatiya Janata Party
DPOs	Organizations of People with Disabilities
DQ	developmental quotient
DRM	disability rights movement
ICD-10	International Classification of Diseases, 10th revision
ICD-11	International Classification of Diseases, 11th revision
ID	intellectual disability
INC	Indian National Congress
IQ	intelligence quotient
MHC Act	Mental Health Care Act, 2017
NDA	National Democratic Alliance
NT Act	National Trust Act, 1999
OBCs	Other Backward Castes
PwD Act	Persons with Disabilities Act, 1995
PwDs	persons with disabilities
PwIDs	persons with intellectual disability
REB	Research Ethics Board
RPwD Act	Rights of Persons with Disabilities Act, 2016
SCs	Scheduled Castes
SLD	specific learning disability
SQ	social quotient
STs	Scheduled Tribes
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

Disability is a major issue around the world, and this thesis examines the case of intellectual disability (ID) in India. The World Health Organization (WHO) estimates that the proportion of the world population with a disability is 16-19% (Saikia, Bora, Jasilionis, & Shkolnikov, 2016). For India the World Bank (2009) has estimated a rate of 5-8%. Regarding ID specifically, a study on India by Arora et al. (2018) reports that ID is found in 3.1% of children aged between 2 to 5 years and 5.2% of children aged between 6 to 9 years. While other sources have offered lower figures, the issue is clearly immense given India's total population of around 1.3 billion people ("India Country Profile," 2019).

The government of India has had programs and policies in place for people with disabilities (PwDs),[1] including people with ID (PwIDs), for many years. For instance, the National Trust, constituted in 1999, operates ten different programs for PwIDs and certain other disabilities (Morgan, 2018). In 2006, the government of India launched the National Policy for Persons with Disabilities to provide education to all children with disabilities until the age of 18 (Girimaji & Srinath, 2010).

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[1] Because people with disabilities are a vulnerable group at risk of a measure of dehumanization, it is a common practice to use terminology that places a term reflecting their common humanity before the term(s) reflecting their disabled status. For instance, "people with disabilities" is used rather than "disabled people," "people with visual disabilities" is used rather than "the blind," and so on. This approach, termed *person-first language*, has been controversial among some people with disabilities and their advocates (Granello & Gibbs, 2016). However, a study by Granello and Gibbs (2016) found that person-first language produced significantly more empathetic responses among respondents. This thesis accordingly uses person-first language throughout.

Despite PwIDs being the target of policies for some time, however, studies show they remain a highly disadvantaged group in society and face many struggles in their efforts to lead dignified, meaningful lives. Prevalent medical, cultural, and religious models of disability lead to the belief that society cannot adapt to accommodate PwIDs, which leaves their caregivers receiving little social support (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010). In general, PwIDs and their caregivers have poor knowledge of legislation and programs intended to help them (Kashyap, Thunga, Rao, and Balamurali, 2012). Specialized health-related services for PwIDs are not available in rural areas, and even urban hospitals rarely have a full range of specialists (Girimaji & Kommu, 2016). PwIDs have long had low life expectancies in India, and while these are beginning to rise, a range of new health problems appears to be emerging in the new population bracket (Lakhan & Ekúndayò, 2017). A minority of PwIDs are confined to long-term institutions, which are plagued by inadequate funding and standards of care and in some cases by abuse, especially of women and girls (Human Rights Watch, 2014).

In 2007, the government of India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). To meet its obligations under that convention, India recently passed a new national law on disability, the Rights of Persons with Disabilities Act, 2016 (RPwD Act).[2] This Act is a comprehensive revision of its predecessor, the Persons with Disabilities Act, 1995 (PwD Act)[3] (Balakrishnan et al., 2019). While the PwD Act covered seven disabilities, the RPwD Act covers 21 (Narayan & John, 2017). The RPwD Act addresses a

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[2] Different sources use somewhat different abbreviations for India’s various pieces of legislation concerning disability. This thesis has standardized the abbreviations.

[3] The law’s full name is the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

wide range of topics, including equality and non-discrimination, protection from abuse, legal capacity, education, employment reservations for government posts, accessibility, health care, rehabilitation, awareness campaigns, and others (Narayan & John, 2017).

Immediate assessments of this law have varied significantly, placing the new legislation at the centre of disability rights controversy in India. Morgan (2018), for instance, lauded it as "a revolutionary Act in India which brought the field of disability from being a charity based initiative to [a] rights based movement through its focus on protection of rights, inclusive education, job reservation, protection of employment, and social security measures." Others, such as Friedner, Ghosh, and Palaniappan (2018), have been critical of the law. Commenting on the passage of the RPwD Act, these authors wrote that it would have little practical effect: "… the state's responsibilities vanish beyond the 4% and 5% reservation in employment and higher education, vague non-discrimination clauses, and token inclusion in general social welfare schemes."

The RPwD Act has been analyzed with regards to disability in general and psychosocial disabilities, but to date only two academic articles include discussion of the law with regards to ID, and neither makes the law's effects on PwIDs its central focus or performs a comprehensive analysis (John, Subramanyam, & Sagar, 2018; Kishore, Udipi, & Seshadri, 2019). This is an important gap not only because of the substantial number of PwIDs who live in India, but also because PwIDs are among the most vulnerable PwDs (Rao, 2008). Thus, how they are treated can serve as a litmus test for how the RPwD Act meets the needs of the most marginalized elements of society. ID is also an "invisible" disability, making it a novel focus of the Act compared to the traditionally dominant categories of hearing disability, visual disability, and locomotor disability in Indian disability discourse (Friedner et al, 2018). This study contributes a comprehensive analysis of the strengths and weaknesses of the RPwD Act with particular focus on the needs of PwIDs in India. It examines the controversies that have arisen around various provisions in the Act and analyzes several sections of the Act that have received less attention. The study brings together a range of sources on the needs of PwIDs as the basis for an assessment of the RPwD Act, supplemented by an exploration of its social and cultural context.

The scope of the research is restricted in several ways to allow for deeper analysis with respect to the narrower topic. The study examines different severities of ID but does not examine the distinct needs of people with genetic disorders under the umbrella of ID, such as Down syndrome and fragile X syndrome. In studying the RPwD Act, the research should not be seen as an attempt at a thorough comparison with its predecessor, the PwD Act, or the UNCRPD, whose standards the RPwD Act was created to meet. Case law based on the RPwD Act is not included. Perhaps most importantly, the research is mostly silent on Indian disability policy, with the hope that limiting the study's scope in this way will allow for more depth on legislative aspects of meeting the needs of PwIDs.[4] Despite these delineations, the needs of PwIDs remains an enormous topic (with several important contested areas), and these needs will be compared to the Act's provisions.

Two points should be clarified on the focus of the thesis. As discussed in the next chapter, the RPwD Act was followed by rules for its implementation in 2017, guidelines for the

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[4] Legislation and policy must be distinguished. Legislation refers to actions of the government legislature (in India's case, a bicameral parliament consisting of the Lok Sabha and the Rajya Sabha), while policy refers to actions of the government that do not require legislative approval. India's disability legislation is a more broad-based statement, while it will be implemented by more specific policies (to the extent it is in fact implemented).

certification of disability in 2018, and an amendment to the rules in 2019. Where the RPwD Act is mentioned in the research questions below, what is meant is the Act together with these supporting documents. More specifically, the needs to be discussed in this thesis are needs that can be met by legislation, with emphasis on needs elided by the medical model of disability and a non-intersectional framework (to be discussed in the "Theoretical Framework" section). These two clarifications apply to the research questions that follow.

Research Objectives

The objective of the research is to assess the extent to which India's recently passed Rights of Persons with Disabilities Act, 2016 (RPwD Act) meets the needs of PwIDs. This broad objective is broken down into five more specific research questions:

1. Among PwIDs in India, what is the distribution of basic demographic characteristics and severities of ID, and how are these characteristics addressed in the RPwD Act?
2. What is the nature of the certification process specified by the RPwD Act for PwIDs and how appropriate is it for the needs of PwIDs?
3. What kinds of needs of PwIDs must be met in order for them to have dignity and equality, and to what extent are these needs adequately addressed by the RPwD Act?
4. What is the nature of the needs of PwIDs with regards to legal guardianship, and to what extent are these needs adequately addressed by the RPwD Act?
5. What is the nature of the health, education, and employment needs of PwIDs and to what extent are these needs adequately addressed by the RPwD Act?

CHAPTER TWO

CONTEXT

This chapter provides the background necessary to understand the findings of the research. It is divided into four parts: first, background information on India; second, an introduction to the topic of ID; third, an overview of disability in India; and fourth, details on the RPwD Act itself.

India

India is the world's second-most populous country ("India Country Profile," 2019). With a total population of approximately 1.3 billion, it is projected to surpass China as the world's most populous country by 2028. India is also the seventh-largest country in the world geographically, covering an area of 3.1 million km^2.[5] According to the 2011 census, India's population is 79.8% Hindu, 14.2% Muslim, 2.3% Christian, and 1.7% Sikh, with all other religious communities representing less than 1% of the country's population each ("India has 79.8% Hindus," 2015).

Along with Pakistan, India gained independence from the United Kingdom in 1947 ("India Country Profile," 2019). It has been a democracy since that time with free and fair elections (The Economist Intelligence Unit, 2018). The centre-left Indian National Congress (INC) party and minor allied parties were in power for most of the years since independence, but lost power to a National Democratic Alliance (NDA) government dominated by the Hindu nationalist Bharatiya Janata Party (BJP) in 2014 (The Economist Intelligence Unit, 2018). India

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[5] This measurement excludes two disputed territories: Jammu and Kashmir and Ladakh.

is a federal country consisting of 28 states and nine Union Territories ("India gets new map," 2019).

India has achieved a sufficient per capita income level to be considered a lower middle-income country (LMIC), but, together with China, it is still home to about half the world's poor people, according to the World Bank (Rahman & Baranyi, 2018). That is, despite high economic growth and great success in poverty reduction over the past two decades, India still has 176 million people living in extreme poverty (World Bank, 2019a). Life expectancy is 67 years for men and 70 years for women ("India Country Profile," 2019). The International Labour Organization estimates that only 2.6% of India's labour force is presently unemployed; that figure has varied by less than half a percentage point since 2010 (World Bank, 2019b). India's health care system is split between the centre and state governments[6] and between private and public systems (Chokshi et al., 2016). As of 2010, 81% of doctors and 58% of hospitals are in the private sector (Thayyil & Jeeja, 2013). The private health care system is concentrated in urban areas (Chokshi et al., 2016).

Intellectual Disability

ID denotes a heterogeneous group of conditions characterized by impaired intellectual ability and, consequently, impaired adaptive functioning (Salvador Carulla et al., 2013). It appears before the age of 18 (Ke & Liu, 2019). If symptoms of ID are detected before a child reaches the age of five, however, the child is instead diagnosed with *global developmental delay* (GDD) (Kishore et al., 2019). The standard practice internationally is that cases of ID are

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[6] It should be noted that in the Indian context, the terms "centre" or "central" are preferred to "national" or "federal." Thus, the national government is referred to as the central government. This thesis adopts this nomenclature.

divided into four categories based on intelligence quotient (IQ) scores: mild (50-69), moderate (30-49), severe (20-34), and profound (below 20) (Ke & Liu, 2019).[7] People with mild ID can usually attain the intellectual capability of an average pupil in the range of Grade 3 to Grade 6, perform an unskilled or semi-skilled job, and look after themselves, whereas people with profound ID can at most barely speak, cannot take care of themselves, and have difficulty expressing emotions (Ke & Liu, 2019). Those with severe and profound ID are thus among the most vulnerable in society. Individuals with IQs from 70-84 cannot be diagnosed with ID but are considered to have *borderline intellectual functioning* (Ke & Liu, 2019).

ID has a wide range of causes, both genetic and environmental; in as many as 40% of all cases, no specific cause can be identified (Ke & Liu, 2019). The most common genetic disorders whose features include ID are fragile X syndrome and Down syndrome, though many other potential genetic causes exist (Ke & Liu, 2019). ID can be divided into syndromic (with other associated features and matching a distinct clinical phenotype) and non-syndromic cases (without other associated features) (Srour & Shevell, 2014). People with autism spectrum disorders (ASDs) often also have ID, but in such a case they receive two separate diagnoses; ASDs are beyond the scope of this thesis. The prevalence of ID worldwide is around 1%, with higher rates in lower- and middle-income countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

ID was formerly referred to as *mental retardation*; however, the term has become associated with stigma toward PwIDs and has thus been out of usage for policy purposes in the

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[7] However, the current system for disability certification in India use a different method, which is discussed at length below.

Western world since the late twentieth century (Chavan & Rozatkar, 2014). That said, the term *mental retardation* is still in use for clinical purposes and will continue to be in use until the WHO's International Classification of Diseases, 11th revision (ICD-11) is released (Kishore et al., 2019). The ICD-11 is expected to adopt the term intellectual developmental disorders (IDD), further complicating the nomenclature (Salvador Carulla et al., 2013; Kishore et al., 2019). This thesis uses the term *intellectual disability*. There is also a complex debate among experts on ID, interrelated with the naming debate, as to whether ID should be understood to be a disability or a health condition (Salvador Carulla et al., 2013). This debate is beyond the scope of this thesis.

Disability in India

Prevalence

The extent of disability in India is not well established. The 2011 census reports the total number of PwDs as 26.8 million, with disability disproportionately common in rural areas, among the elderly, among males, among Scheduled Castes (SCs), and (to a lesser extent) among Scheduled Tribes (STs)[8] (Saikia et al., 2016).[9] As a proportion of the population, this means 2.21% of Indians have one or more disabilities (Kumar, Premarajan, Kattimani, & Kar, 2018). The following lines of evidence suggest this figure is too low, however. Bhaskar and Kumar (2013) highlight a series of limitations in census data collection that have led to under-enumeration of people with disabilities. Saikia et al. (2016) compare the census figure to a WHO estimate that 25% of India's population has some form of disability (well above the global

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[8] SCs and STs are the most disadvantaged groups in the Indian caste system. Caste will be further discussed in the "Theoretical Framework" section.

[9] The reasons for demographic imbalances in the prevalence of disability will be discussed in Chapter 7.

average), arguing that the massive discrepancy could be due to both divergent definitions of disability (the census used a medical definition) and major potential sources of error in both sources. Two studies in rural Chandigarh and Karnataka estimate the prevalence of disability at 4.8% and 6.3% respectively, much higher than the census reported (A. Singh, 2008; Kumar et al., 2008b).

Arora et al. (2018) analyze a large sample from five sites across India and find that 9.2% of children aged 2-5 and 13.6% of children aged 6-9 have at least one neurodevelopmental disorder (a category they define more broadly than this thesis has defined mental disability). Kumari et al. (2009) estimate 1-2% of people have a mental disability (including psychosocial disability and ID), and the percentage was even lower in some localities they surveyed. They find that mental disability disproportionately affects people of low socioeconomic status and males (though they hypothesize that females are under-reporting due to higher stigma). In general, data on PwDs from ethnic and religious minorities is scarce (Centre for Sustainable Use of Natural and Social Resources & Minority Rights Group International, 2019). An analysis of disability certificates issued for mental disability from 2006 to 2008 shows that the vast majority were for ID, while the remainder were for psychosocial disability, mainly schizophrenia (Kashyap et al., 2012).

Estimates for the prevalence of ID in India vary even more widely. The 2011 census found that only 5.6% of PwDs had ID (Kumar et al., 2018). Girimaji and Srinath’s 2010 literature review on ID finds estimates ranging from 1 to 32 cases per 1,000 people; they explain that the wide range is based on differences in sample populations, methodologies, and definitions. More recently, Sharma and Ramakrishna (2013) report 3 cases per 1,000 people in rural areas and 5 per 1,000 in urban areas (the opposite of the discrepancy for disability overall reported in the census), while Lakhan, Ekúndayò, and Shahbazi (2015) give a higher estimate of 10.5 cases per 1,000. Arora et al. (2018) report that 3.1% of children aged 2-5 in their sample and 5.2% of children aged 6-9 have ID; the latter figure is significantly higher than any of those reported above.

Policies

In India, disability affairs are the responsibility of the Department of Empowerment of Persons with Disabilities (Divyangjan),[10] which falls under the Ministry of Social Justice and Empowerment (Morgan, 2018). Currently, only 8 of 100 ministries and departments discuss disability in any way in their policies, demonstrating a lack of mainstreaming of disability in the Indian government (National CRPD Coalition-India, 2019). For the last three years, spending on PwDs has been approximately constant in India's federal budget, at a mere 0.02% of total spending (National CRPD Coalition-India, 2019). Disability benefits in India are contingent upon receiving a disability certificate. Disability benefits, such as a disability pension, are provided both by the central government and individual state governments (Social Welfare Department (Government of Chhatissgarh), 2018; e.g., Directorate of Welfare of Disabled and Senior Citizen (Government of Karnataka), 2019). Despite the existence of these many programs, Kashyap et al. (2012) report that 99% of people in rural areas certified with ID do not collect any benefits except the monthly pension. Lakhan and Sharma (2010) similarly find that

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[10] The term *divyangjan* means "those with divine abilities." It is a term introduced by the NDA government for people with disabilities, but it has been criticized by disability rights activists (Salelkar, 2016; Kannabiran, 2016). Nevertheless, this thesis has included it in the department's name because it is part of the official nomenclature.

parents are often unaware of legislation to support PwIDs; for their part, those with ID are generally unable to navigate the relevant institutions themselves.

The National Trust, constituted under the National Trust Act, 1999 (NT Act),[11] operates ten different programs for PwIDs and people with certain other disabilities, including early intervention for those aged 0-10, pre-vocational and vocational training for those aged 11-18, group homes for adults with severe disabilities, assistance for aids and appliances, and more (Morgan, 2018). The National Institute for the Empowerment of Persons with Intellectual Disability, an autonomous Indian government organization, was founded in 1984 (Rao, 2008).[12] A comprehensive disability policy, the National Policy for Persons with Disabilities, was announced by the government of India in 2006 (Girimaji & Srinath, 2010). This policy sets out to provide all children with disabilities with free preschool, primary school, and secondary school by 2020 (Morgan, 2018). The government of India has recently switched to using the term *intellectual disability* rather than the term *mental retardation* for policy purposes, though not yet for clinical purposes (Kishore et al., 2019).

Legislation

India's disability legislation is composed of four laws (United Nations Development Programme, 2012). India recently passed revised versions of two of them: the RPwD Act, which replaced the PwD Act, and the Mental Health Care Act, 2017 (MHC Act), which replaced the Mental Health Act, 1987. The MHC Act does not cover ID. The NT Act is a third law on

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[11] The law's full name is the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

[12] The institute recently acquired this name; it was formerly known as the National Institute for the Mentally Handicapped (Yadav & Arora, 2019).

disability, which created the National Trust, a body whose activities were touched upon above. Lastly, the Rehabilitation Council of India Act, 1992 regulates training and research surrounding rehabilitation for people with disabilities (UNDP, 2012).

Disability is also discussed in a wide variety of Indian laws whose main subject is not disability. Around 150 such laws discriminate based on disability (National Disability Network & National Committee on the Rights of Persons with Disabilities, 2019). These have not yet been brought up-to-date with India's obligations under the UNCRPD (National CRPD Coalition-India, 2019). Also, India has yet to sign the Optional Protocol to the UNCRPD (National CRPD Coalition-India, 2019).

Disability Rights Movement

India's disability rights movement (DRM) emerged out of the self-advocacy movement of people who are blind in the 1980s (Chander, 2016). To make its concerns heard, it initially resorted to "contentious" political strategies such as rallies, picketing, and hunger strikes (Chander, 2016). At this point there is a split in historiography. Mehrotra (2011) writes that the DRM's influence was minor compared to international activism in the passing of the PwD Act in 1995, whereas Chander (2016) attributes the Act's passage to the DRM's persistent campaigning. In either case, the DRM played at least some role in bringing about India's disability rights law, demonstrating the agency of PwDs to advocate for themselves.

Following the passage of the PwD Act in 1995, the movement mainly re-purposed itself toward political lobbying to have the provisions of the PwD Act implemented (Chander, 2016). At this time, the movement also took on more of a cross-disability character, continuing to agitate successfully for a variety of concessions (Chander, 2016). There is a large confederation of parents of people with intellectual and developmental disabilities in India known as Parivaar (Girimaji & Kommu, 2016). Arguing against the idea of a united cross-disability movement, Friedner et al. (2018) have drawn attention to significant tensions between groups of PwDs within the DRM. Since the RPwD Act was passed, DPOs have contributed several reports to the United Nations Committee on the Rights of Persons with Disabilities, a body that monitors compliance with the UNCRPD. In response to pressure from disability rights activists, the Department of Empowerment of Persons with Disabilities (Divyangjan) issued three memorandums to all states and Union Territories on November 22, 2019, urging states to meet their responsibilities under the RPwD Act, including specifically providing employment reservations and ensuring non-discrimination (S. Baranyi, personal communication, November 28, 2019).

The RPwD Act

History

The genesis of the RPwD Act was India's ratification of the UNCRPD in 2007, which legally required it to update the PwD Act to meet the UNCRPD's provisions (Balakrishnan et al., 2019). The process of drafting the bill began in 2009 (Math, Gupta, Yadav, & Shukla, 2018). PwDs were widely consulted in preparation for the drafting of the RPwD Act (Friedner et al., 2018). However, significant tensions existed between diverse groups within the DRM, particularly between people with the traditionally central disabilities (visual, hearing, locomotor) on the one hand, and parents of children with ID and ASDs on the other (Friedner et al., 2018). The INC-led government attempted to rush a version of the bill through the legislature shortly before handing over power to the BJP in 2014, but this was not successful (Friedner et al., 2018).

Two previous versions of the bill were tabled, before the final version of the bill was introduced in 2014 (Disability Rights Promotion International, 2017). At this stage significant changes were made to the earlier version without consultation members of the DRM (National CRPD Coalition-India, 2019). The RPwD Act was finally passed in December 2016 (John, Subramanyam, & Sagar, 2018).

Many provisions of the law were left with unspecified details to be clarified in future rules and guidelines, and accordingly the rules for the law's implementation were approved in June 2017 and the guidelines were approved in January 2018 (Gazette of India (Extra-Ordinary), 2016; 2017; 2018; John et al., 2018). Following consultations, a short amendment to the 2017 rules was passed in 2019 (Gazette of India (Extra-Ordinary), 2019b). To my knowledge, there has been only one further set of government rules issued to supplement the RPwD Act, and, as it only concerns employment criteria for a single government post, I do not believe it merits further discussion in this thesis (Gazette of India (Extra-Ordinary), 2019a).

Content

The RPwD Act is India's central piece of legislation on disability. It covers a wide range of topics; it consists of 102 sections grouped into 17 chapters for ease of understanding, followed by a Schedule (Gazette, 2016; John et al., 2018). After the law defines terms (Chapter 1), it covers the rights of PwDs (Chapter 2); education (Chapter 3); employment and related topics (Chapter 4); and disability benefits, healthcare, and related topics (Chapter 5). Next are special provisions to help people with benchmark disabilities (Chapter 6) and provisions to identify and help people with benchmark disabilities and high support needs (Chapter 7). The later chapters cover practical provisions, that is, responsibilities of the government (Chapter 8), registration of

DPOs (Chapter 9), the certification process people must follow to be accorded disability status (Chapter 10), central and state advisory boards (Chapter 11), central and state commissioners (Chapter 12), a special court to prosecute offences under the Act (Chapter 13), central and state funds (Chapters 14 and 15), and penalties for violations (Chapter 16). Lastly, Chapter 17 includes miscellaneous provisions, mainly lists of details that are left to the central and state governments, which must be established within six months.

Following the main body of the law is the Schedule, which specifies the types of disabilities covered by the RPwD Act (21 in total) and gives brief definitions of them (Gazette, 2016). Among the disabilities recognized by the RPWD Act, ID, psychosocial disability, specific learning disorder (SLD) and ASDs are mental disabilities (Narayan & John, 2017). Outside the Schedule and the definitions section, the RPwD Act seldom mentions specific disabilities; ID is mentioned only three times. While each of these three provisions is discussed below, most of the analysis in this thesis turns on the vastly more numerous provisions for PwDs in general.

The rules for the RPwD Act were published in 2017 to provide specific details on subjects that were deliberately stated only in general terms in the Act itself (Gazette, 2017). For instance, they give rules for the accessibility of buildings to PwDs. The later part of the rules includes eight forms formalizing various processes related to disability, three on employment of PwDs and five on the certification of disability. The 2019 amendment to the rules for the RPwD Act specifies the rubric according to which a person may be judged to have high support needs (Gazette, 2019b). The 2018 guidelines are the other significant addition to the law; the important provisions are in Annexure II, which gives the diagnostic criteria for assessing whether a person has a disability (Gazette, 2018). Section IV of the annexure gives the criteria for assessing ID and SLD.

CHAPTER THREE

LITERATURE REVIEW

A substantial amount of academic literature and grey literature discusses PwIDs in India. Although this literature covers many topics, this literature review focuses on two key areas: the needs of PwIDs and analysis of the RPwD Act.

Needs of PwIDs

This section of the literature review covers social attitudes, institutionalization, privacy, health, education, and employment.

Social Attitudes

Discrimination and stigma toward PwDs are reported in multiple sources. Kumar et al. (2012) report deep-seated fear of people with disabilities and resulting segregation and they attribute these fears to cultural and religious factors. In a similar vein, Chandrashekar et al. (2010) note the presence of stigma and discrimination toward people with psychosocial disability. They write that people with psychosocial disability are often denied benefits such as bus passes because they do not look disabled. Rao et al. (2016) state that due to the "invisibility" of psychosocial disability, people affected by it suffer more pervasive discrimination than people with physical disabilities. I believe these two articles to be relevant because ID is also a type of "invisible" disability.

Four studies have examined social attitudes toward PwIDs specifically. Two old studies from 1990 and 1993 showed that awareness of ID was poor in India but that awareness programs could help (Scior, 2011). Edwardraj et al. (2010) report survey results from focus groups of mothers, health workers, and teachers. They find various overlapping medical, cultural, and religious models of disabilities exerting a major negative impact on the lives of PwIDs in India and leading to caregivers receiving little social support. Lakhan and Sharma (2010) analyze the knowledge, attitudes, and practices of families in India and find that parents frequently believe that ID is punishment for sins in past lives, that it can be cured by faith healers, or that maladaptive behaviors should be rectified through punishment.

Institutionalization

One of the issues facing PwIDs is involuntary confinement to institutions or to their homes (Committee on the Rights of Persons with Disabilities, 2019a). There is a lack of awareness in communities concerning women with ID and psychosocial disabilities, leading to their institutionalization, after which they are often subject to violence (Women with Disabilities India Network, 2019). Women and girls with ID and psychosocial disability are frequently subject to appalling living conditions after being forcibly institutionalized (Human Rights Watch, 2014). The institutionalization of children with ID has led to the Asha Kiran complex, which is intended to house 350 children, housing over 900 (Haidar, 2017). There have been numerous reports of degrading living conditions in the complex and the institution has experienced a staggering death toll of over 600 since 2001 (National CRPD Coalition-India, 2019). While these hardships are severe, the vast majority of PwIDs in India live with their families, not in institutions (Girimaji & Kommu, 2016). Kashyap et al. (2012) report that only 6.8% of those certified with ID are confined to institutions. Unfortunately, there is a paucity of research on the strengths and weaknesses of alternative models of support for people with no other home.

Privacy

Mishra, Parker, Nimgaonkar, and Deshpande (2012) argue that the current system of disability certification violates the privacy of PwDs with “invisible” disabilities such as ID that can be concealed. This is because disability certificates contain information about the nature and extent of their disabilities that must be presented to various officials such as railway ticket officers who are not legally bound to keep information confidential. When information about a person’s disability is revealed it can result in social stigma. Similar concerns are voiced by Karkal and Shihabuddeen (2014) and Sarkar (2018). Mishra et al. (2012) propose that in addition to a disability certificate, PwDs be issued a separate document with their name, a photograph, and a statement of what benefits they are eligible for, but not a statement of the nature and severity of their disability. These authors argue that PwDs could then be identified in a way that simultaneously allows access to benefits, protects privacy, and prevents fraud.

Health

Existing literature suggests PwDs in India lack access to adequate rehabilitation and health services. Few PwDs manage to access rehabilitation services, whereas a rough estimate suggests two thirds need them (Kumar, Roy, & Kar, 2012). Accessibility issues also make it difficult for PwDs to access health services more generally (Kumar et al., 2012).

Lakhan and Ekúndayò (2017) note that life expectancy has been rising for PwIDs in India, clearly a positive development and yet also the source of a new range of health problems among PwIDs. While there are no good data for India, PwIDs in developed countries are likely to lead a sedentary lifestyle; this is quite possibly the case in India too, meaning a range of chronic diseases such as cardiovascular disease could be disproportionately common among adults with ID in India (Lakhan & Ekúndayò, 2017). Inferring once again from data from the developed world, there may also be a problem with substance abuse among PwIDs who have had opportunities to participate in community activities, despite community participation being otherwise desirable (Lakhan & Ekúndayò, 2017).

Lakhan and Kishore (2016) report that mortality among adults with ID in India rises significantly beginning in early adulthood, though they say sufficient research does not exist to determine the causes of this increase. Major disparities in health care for PwIDs exist between urban and rural areas in India (Girimaji & Kommu, 2016). Literature reviews by Girimaji and Srinath (2010) and Chavan and Rozatkar (2014) both note the need for prevention efforts to reduce the incidence of ID. It is also important to reduce the incidence of chronic health conditions among PwIDs in India by addressing their causes, or else large costs will be incurred on the health care system later on by the necessary treatments (Lakhan & Ekúndayò, 2017).

A small proportion of PwIDs also have other disabilities (Girimaji, 2008). People with any combination of disabilities are referred to as having *multiple disability* under the RPwD Act (Gazette, 2016). ID also has comorbidities with a range of other medical, behavioral, and psychiatric diagnoses (Kishore et al., 2019). These comorbidities include conditions such as hearing impairment and visual impairment, and therefore overlap with multiple disability. One particularly common comorbidity is epilepsy, with a prevalence of 15-30% among PwIDs and about 50% among people with severe ID (Kishore et al., 2019). Around 40% of PwIDs in India have another psychiatric condition, meaning the prevalence of psychiatric disorders is three to five times what it is for the Indian population on average (Kishore et al., 2019).

Education

A program named Sarva Shiksha Abhiyan was launched by the government of India in 2001 to achieve universal primary education, including for all children with special needs (Singh, 2016). However, a 2013 government of India study found that 36% of children aged 6-13 with mental disabilities are not in school (Chadha, 2019).

Education is as important for children with ID as it is for children without ID, if not more important (Ke & Liu, 2019). While children with ID typically struggle in school, with proper methods and support they can learn (Ke & Liu, 2019). PwIDs nonetheless have one of the lowest rates of school enrollment among PwDs in India (Committee on the Rights of Persons with Disabilities, 2019b). Rao (2008) emphasizes the importance of rehabilitation professionals and of favorable attitudes among teachers and the community.

The current trend in education policy in the world is for students with ID to be incorporated into normal classes with other children (Ke & Liu, 2019). This approach is called *inclusive education*; the alternate approach, of placing them in separate classes where they can receive extra attention and help, is called *special education*. Different philosophical frameworks argue either for inclusive education for all children with disabilities as long as they learn something, even if they do not keep pace with other children, or special education for more children with more severe disabilities (Rao, 2008). 6.6% of people certified with ID in urban areas were attending special schools, based on data from 2006 to 2008 (Kashyap et al., 2012). India's disability rights sector remains divided on the issue of special versus inclusive education (National CRPD Coalition-India, 2019).

Four articles from India discuss inclusive and special education with respect to ID and all of them assert the value of inclusive and special education for different severities of ID. According to Rao (2008) and Chavan and Rozatkar (2014), while inclusive education benefits children with mild to moderate ID, children with severe and profound ID benefit more from special education or homeschooling. Balakrishnan et al. (2019) state that those with moderate or severe ID as well as students with high support needs will likely not do well in the context of inclusive education. Lakhan (2013) analyzes the results of a community-based rehabilitation project for PwIDs aiming to enroll them in inclusive schools. He measures the rate at which they were able to attend regular schools and finds that most children with borderline or mild ID as well as some children with moderate ID were successful, but that no children with severe or profound ID were able to be included for various reasons.

Employment

There is very little in the academic literature on employment of PwIDs in India. Chavan and Rozatkar (2014) note the importance of vocational training for PwIDs in order to promote employment, but their literature review reports no data on the rate of employment of PwIDs. Naraharisetti and Castro (2016) analyze 2001 census data on the employment of PwDs, finding that in rural areas people with mental disabilities are the PwDs least likely to be employed, but that in urban areas people with mental disabilities are more likely than other PwDs to be employed. A 2017 report by Disability Rights Promotion International discusses results of interviews with PwDs and shows that they face a range of attitudinal barriers in their efforts to find work as well as in the workplace once they find it.

Analysis of the RPwD Act

This section explores existing literature that has assessed the RPwD Act from three perspectives: overall, with reference to psychosocial disability, and with reference to ID. It includes psychosocial disability because like ID it is an "invisible" disability and thus concerns for people with psychosocial disability are similar to those for PwIDs. The reception of the RPwD Act has been mostly been positive but there have been some criticisms.

Overall

A large amount of academic and grey literature has assessed the RPwD Act overall. Academic reception has been mostly, though not entirely, positive. Morgan (2018) calls the RPwD Act "a revolutionary Act in India which brought the field of disability from being a charity based initiative to [a] rights based movement through its focus on protection of rights, inclusive education, job reservation, protection of employment, and social security measures." Gupta (2017) presents a critique of the Act, focusing on a range of specific issues, mainly concerning how the Act will affect people with particular disabilities, including intellectual disability. Rani (2018) analyzes the RPwD Act with regards to inclusive education, listing a large number of strengths of the legislation and a small number of weaknesses. Also with regards to education, Kumar and Kumar (2018) explore the RPwD Act's relevant provisions, concluding with strong praise. Nanda (2019) heavily praises the RPwD Act, making only one suggestion for change: that each school be required to have at least 5% of students with disabilities to prevent certain loopholes from undercutting the provisions on inclusive education. The RPwD Act was assessed with regards to employment by Sarkar (2018), who gave a generally positive analysis as well as discussing possible steps beyond legislation. Friedner et al.

(2018) discuss the RPwD Act and the controversies during its formulation, including some reference to tensions between people with visual, hearing, and orthopedic disabilities and parents of PwIDs (along with parents of people with ASDs). They discuss ID specifically only in the context of the law's limited guardianship provision, and they do not take a position on its value. Most sections of the law are discussed briefly or not at all.

Several DPOs released reports in 2019 assessing India's compliance with the UNCRPD, generally praising the RPwD Act. The National Centre for Promotion of Employment for Disabled People (2019) called the RPwD Act "very strong [legislation]" and "in line with the spirit and values of the UNCRPD," though it did object to a section allowing for exceptions to non-discrimination provisions. Two Indian organizations, the National Disability Network and the National Committee on the Rights of Persons with Disabilities (2019) call the RPwD Act (along with the MHC Act) a "positive" development, though they are critical of a few provisions including the system of limited guardianship, which can deprive PwDs of legal capacity at the behest of a court. India's National Human Rights Commission likewise released a (briefer) 2019 report on India's compliance with the UNCRPD, which called the RPwD Act "a very progressive piece of legislation and in line with the UNCRPD."

Regarding Psychosocial Disability

Three articles discuss the RPwD Act in its final form with reference to people with psychosocial disability, all of which criticize certain aspects of the Act. Narayan and John (2017) are critical of the Act for granting too much freedom to people with psychosocial disability who lack appropriate mental capacity; the authors feel the law should have greater coercive power over these people. Math et al. (2019) criticize some aspects of the Act, such as the requirement for professionals from particular specialties being required for certification in the 2018 guidelines. Balakrishnan et al. (2019) praise many aspects of the Act, such as the increased number of recognized disabilities, while criticizing several others, such as a lack of more specific guidelines on inclusive education.

Regarding ID

While there are two academic articles discussing the RPwD Act with reference to ID, neither goes beyond the topic of certification. John, Subramanyam, and Sagar (2018) discuss the 2018 guidelines for the RPwD Act, with regards to ID, ASDs, and SLD, though they do not assess the Act itself. They mainly focus on SLD but do criticize the assessment criteria for ID for neglecting the role of clinical assessment. Kishore et al. (2019) provide clinical guidelines for the diagnosis of ID, but in so doing they also provide a comparison of the RPwD Act's definition of ID with those in the ICD-10, the ICD-11 working group, and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). They also summarize the 2018 guidelines for certifying ID, but at no point seek to commend or critique any of the RPwD Act's provisions.

CHAPTER FOUR

THEORETICAL FRAMEWORK

This thesis interprets its findings in light of two main theoretical paradigms: the biopsychosocial model of disability and intersectionality.

Biopsychosocial Model of Disability

Disability is a complex issue and as such has been conceptualized in a variety of different ways. This section explores a series of models as a way of explaining the benefits of the biopsychosocial model of disability. Religious models were historically dominant, but with the rise of science and modern medicine, they were displaced by the *medical model of disability* (Haegele & Hodge, 2016). The medical model assumes that disability results directly from *impairments* (Haegele & Hodge, 2016). Impairments are functional difficulties with people's bodies or minds, such as a missing leg or a cognitive difficulty with reading. Thus, according to the medical model, those two examples of impairments are synonymous with locomotor disability and reading disability (dyslexia), respectively. This model gives considerable importance to doctors and other medical professionals, who are expected to refer individuals with disabilities for treatment, diagnose their conditions, and prescribe ways to "fix" their impairments as much as possible to facilitate a greater level of participation in society (Haegele & Hodge, 2016).

The *social model of disability*, a critique of the medical model, emerged in the 1960s in the United Kingdom, the term being coined by Mike Oliver in 1983 (Shakespeare, 2006). Under this model, disability is seen as a unique characteristic, not a problem, and the goal is for society to adapt so that PwDs can be included as equal members (Haegele & Hodge, 2016). This model draws a sharp distinction between impairment and disability; while impairments are intrinsic to the individual, it is only if society fails to accommodate them that the individual becomes disabled (Haegele & Hodge, 2016). From this vantage point, legislation (such as the RPwD Act) and policy should not only provide medical services but also work towards making society more inclusive for PwDs. The social model thus decreases the relative importance of doctors and also makes PwDs themselves as well as advocates central to efforts towards greater equality (Haegele & Hodge, 2016).

Haegele and Hodge (2016) provide a powerful illustration that captures the difference between the medical and social models of disability. They consider a hypothetical student with a visual impairment and how two physical education teachers would treat her. The first teacher, thinking in terms akin to the medical model, would design a curriculum with children without impairments in mind and would make only minor adjustments to suit the student with a visually impairment, attributing the student's failure to fully participate to her impairment (Haegele & Hodge, 2016). The second teacher, thinking in terms akin to the social model, would design a curriculum with all students in the class in mind, for example using rattle soccer balls so the student can follow them by hearing (Haegele & Hodge, 2016).

The social model has largely displaced the medical model in academia (Friedner et al., 2018). Nevertheless, a number of scholars have in turn challenged the social model. Lakhan and Ekúndayò (2017), for example, write that the shift in the way ID has been discussed and responded to in the last three decades, toward the social model of disability, has led to insufficient emphasis on health challenges also faced by PwIDs. Several academics have advocated a model according to which disability emerges from complex interactions between bodily impairments and social marginalization (see e.g., Marks, 1999; Shakespeare, 2006; Fitzgerald, 2006; Haegele & Hodge, 2016). This model has also been adopted by the WHO's International Classification of Functioning, Disability and Health, the UNCRPD, and the WHO and World Bank's 2011 World Report on Disability, under the name *biopsychosocial model of disability* (World Health Organization & World Bank, 2011).

This model can be seen as a synthesis of the medical and social models in that it regards individual impairments as important in the manner of the medical model, and yet emphasizes that these on their own do not constitute disability, which is rather a product of the interaction of impairment with outside factors (WHO & World Bank, 2011). Specifically, the UNCRPD states that disability results from the interaction between 1) impairments, 2) attitudinal barriers (i.e. those resulting from the attitudes a society holds towards PwDs), and 3) environmental barriers (i.e. those resulting directly from the physical and social environment, such as the lack of a sign language interpreter for a person with a hearing disability or the lack of a wheelchair-accessible bathroom in a building) (WHO & World Bank, 2011). The strength of a model that considers both medical and social factors is not surprising given that, as already discussed, ID originates from a combination of genetic and environmental causes (Ke & Liu, 2019). Marks (1999) also notes the importance of the PwD's emotional life as an important mediating space, where anxiety, despair, and internalized feelings of self-blame, for example, influence the way in which disability is experienced.

Two additional models are the *charity-based model of disability* and the *rights-based model of disability*. The charity-based model of disability holds that PwDs are helpless and need to be supported by other people (Sarkar, 2018). The rights-based model aims to bring PwDs full participation in society, equal opportunities, and freedom from discrimination through the fulfillment of human rights (Kelemen & Vanhala, 2010; Sarkar, 2018). Historically, the rights-based model has been closely tied to the social model (Sarkar, 2018). This thesis adopts the rights-based model as supplementary to the biopsychosocial model, because it is especially appropriate for analyzing disability rights law.

Mckenzie (2013) reviews the medical and social models as they apply to ID and makes an argument for using the biopsychosocial model based on her research in South Africa. Her results are based on the results of survey questions posed to PwIDs, people who worked with PwIDs, and people who had children with ID. She first had them rate the accuracy of a list of statements about ID and then performed two levels of factor analysis to extract correlated groups of statements. Four discourses emerged, with the first three roughly corresponding to the medical model, the social model, and the biopsychosocial model, and the last discourse relating to community. She concludes that the "interactive" discourse, which she links to the biopsychosocial model, is most useful because it opens the possibility that ability is based on the relationship between the individual and their context. To my knowledge, the existing literature on India does not discuss the value of the different models of disability with specific respect to ID, however. This study is therefore the first to explore this theoretical terrain.

Intersectionality

Intersectionality is a theoretical framework proposed by Kimberlé Crenshaw in 1989 to understand the experiences of black women in the United States (Carbado, Crenshaw, Mays, & Tomlinson, 2013). It explores the interactions, or "intersections," between multiple forms of marginalization, making an effort to cast light on the otherwise underemphasized experiences of people at these intersections (Carbado et al., 2013). In terms of theoretical background, intersectionality is diverse, drawing on critical race theory and black feminism, though it goes beyond them and critiques them both (Carbado et al., 2013). It has since blossomed into a full-fledged paradigm that reaches diverse disciplines, countries, and forms of social marginalization (Carbado et al., 2013).

Social status and marginalization are complex phenomena in India, as in any part of the world, with dimensions including gender, socioeconomic status, caste, skin color, rural vs. urban setting, and religion, among others, and of course disability (including multiple disability, although it is beyond the scope of the thesis). Brief background on other forms of marginalization will help shed light on the circumstances of PwIDs whose identities intersect with these groups. Haq (2013) applies the theoretical framework of intersectionality to women in India. She gives an overview of Indian patriarchal attitudes and customs, covering subordination to men, dowry deaths, sex-selective abortion, and mistreatment of widows. She highlights religion, caste, and skin color as dimensions of marginalization prevalent in Indian society that compound marginalization based on gender. Regarding religion, she mentions a number of Hindu practices toward women that have been outlawed but persist nonetheless. She also mentions the plight of Muslim women in particular owing to discriminatory provisions in the Shariat Muslim Personal Law that continues to govern matters such as inheritance in India's Muslim community (whereas for non-Muslims these issues fall under secular law). Regarding skin color, Indian women are under heavy pressure to artificially lighten their skin or else risk jeopardizing their marital and professional prospects (Haq, 2013).

Lower castes and minority religious groups are also highly relevant from an intersectional perspective. The Indian caste system is a complex and dynamic social hierarchy influenced by political, economic, religious, and cultural factors (H. Singh, 2008). As noted above, the most disadvantaged groups in the hierarchy are known by the government of India as Scheduled Castes (SCs) and Scheduled Tribes (STs) (Maity, 2017). (Readers not familiar with the Indian caste system may consult Appendix B for more background on this highly complicated topic.) While Haq (2013) discusses religion as the cause of marginalization (of women), religious minorities are also the subject of marginalization. Muslims are India's largest religious minority and also its most socially and economically disadvantaged religious group (Centre for Sustainable Use of Natural and Social Resources & Minority Rights Group International, 2019). Jahan (2016) discusses the marginalization of Indian Muslims from an intersectional perspective, finding not only that Muslims are socioeconomically disadvantaged and geographically ghettoized, but also that Muslim women and Muslims of low caste suffer disproportionately. Muslims and Christians who are members of SCs, unlike Hindu, Buddhist, and Sikh members of SCs, do not qualify for government affirmative action programs ("Thirumavalavan wants Scheduled Caste tag," 2019). Unexpectedly, some religious minorities such as Sikhs and Parsis enjoy disproportionately high socioeconomic status (Alavi, 2011; Buck, 2017).

In the new millennium, disability studies both internationally and in India has experienced an "intersectional turn" (Friedner et al., 2018). To my knowledge, however, there exists no article that discusses intersectionality with reference to PwIDs in India. This thesis thus opens new theoretical ground by discussing other forms of marginalization in the context of issues facing PwIDs. Intersectionality is highly relevant to the thesis' first research question, which analyzes the distribution of demographic characteristics among people with ID and how these characteristics are addressed by the RPwD Act. Intersectionality also remains relevant throughout the “Results” and “Discussion” chapters because issues such as education, institutionalization, and employment reservations affect certain marginalized groups more than others. For instance, special schools are rarely available in rural areas, and women and girls are more likely to face abuse in institutions. This thesis gives special attention to people at the intersections of ID and other types of marginalization.

There is one final complexity to be noted concerning intersectionality. PwIDs who are women, members of SCs and STs, Muslims, people in rural areas, or people of low socioeconomic status are disproportionately marginalized, but these groups do not in all cases have the highest prevalence of ID. STs have a rate of ID well below average, and women are less likely to have ID than men are (Office of the Registrar General & Census Commissioner, India, 2013). In the latter case the true size of the gap may not be known precisely, but there is good reason, as will be discussed in Chapter 7, to believe men really do have a higher rate of ID. This thesis will nevertheless give special attention to the case of women instead of men because, while women are less affected numerically, they are more affected individually; there are fewer women with ID but the average woman with ID faces more barriers than the average man with ID. The same can be said for STs or any other marginalized group with a lower-than-average prevalence of ID.

CHAPTER FIVE

METHODOLOGY

To provide an in-depth understanding of the RPwD Act with respect to this study's research objectives, a qualitative research methodology has been adopted. This approach allows for a detailed, contextual, and nuanced understanding of the new law as it relates to the needs of PwIDs. The study employs three complementary research methods: 1) review, synthesis, and critique of academic and grey literature, 2) document analysis of the RPwD Act and supporting documents, and 3) conducting interviews via Skype. This chapter discusses these three methods in turn, then discusses the criteria the thesis uses to judge the RPwD Act, and concludes with reflections on my positionality as a researcher.

Synthesis of Existing Literature

The literature review for this thesis draws on two types of existing source materials. The first is the substantial body of previously published academic literature on the topic of ID in India, most of which originates in India. The literature was valuable both because of the body of work establishing the needs of PwIDs in India and because of the smaller body analyzing the RPwD Act before and after it was passed. Databases used included JSTOR, Google Scholar, the University of Ottawa library online database, and the *Indian Journal of Psychiatry*, while search terms used included "India" in combination with "disability," "mental disability," "intellectual disability," "Rights of Persons with Disabilities Act, 2016," and "women." Because of the large volume of material available on the topic, results older than 2005 have only occasionally been included. The literature on psychosocial disability in India was also used because many of its concerns parallel those applicable to ID, though the body of literature on psychosocial disability was too large to allow for a systematic survey. Literature on India connecting to the study's theoretical framework or related areas such as caste and religion was also investigated to a lesser extent. The full search yielded 71 relevant academic articles on India once articles that were related but out of scope were removed. Bodies of international literature that were queried but not systematically surveyed include disability theory, intersectional theory, positionality theory, general research on ID, research on inclusive and special education for PwIDs, and some other topics. These yielded an additional 23 relevant academic articles.

The second type of source materials this the research drew upon was grey literature, comprising international, governmental, and NGO/DPO reports on relevant topics as well as Indian legislation other than the RPwD Act. A key database that was surveyed systematically is found on the United Nations Committee for the Rights of Persons with Disabilities website. This database and other searches produced 27 documents of value for the thesis. In addition, news articles from reliable journalistic sources were used occasionally when certain facts were unavailable elsewhere.

Document Analysis

The second element of the research methodology was analysis of the text of the RPwD Act itself, together with its 2017 rules, its 2018 guidelines, and the 2019 amendment to its rules. Associated rules, guidelines, and so forth to the RPwD Act are published in the Gazette of India; the contents of this publication number in the thousands per year and so could not be systematically surveyed even for the period since the RPwD Act was passed in December 2016, but keyword searches in the Gazette database and mentions in published literature on the law were used to locate the main supplementary provisions to the Act itself (i.e., those just mentioned).

Interviews via Skype

In addition to the existing literature and analysis of the RPwD Act and its supporting documents, this thesis included long-form interviews conducted by Skype with people with relevant expertise. Those who were contacted were drawn from three groups: 1) representatives of Indian and international DPOs, 2) researchers who have published on relevant issues, and 3) Indian officials responsible for disability policy. The primary criterion for the choice of potential interviewees to be contacted was falling into one of those three groups, while secondary criteria were prominence, specific relevance, and unique focus (as compared to other interviewees). For researchers, specific relevance was established by studying the publication histories of authors of academic articles that were valuable for the thesis' literature review. For DPO representatives, specific relevance was established by the recommendations of intermediate contacts.

The recruitment process was as follows. Potential participants were initially contacted by email (see Appendix C for a sample recruitment email). Those who agreed to participate were then sent copies of the consent form prepared for the research and approved by the University of Ottawa's REB (see Appendix D). Throughout the process of recruitment and interviews, a spreadsheet was maintained that tracked who was contacted, when they were contacted, whether they responded, and when interviews were ultimately conducted. All communication was in English, which is widely spoken by India's educated and professional classes (Sebastian, 2018). With the invaluable help of certain intermediate contacts, 43 potential interviewees were contacted in total. Nine interviews were conducted and an additional four people agreed to participate but were unavailable until too late in the study's timeframe. Of the nine participants, five have been categorized as researchers and four as DPO representatives, though in some cases one person's work straddled multiple domains. No officials responded to interview requests, although one researcher was formerly of a government background. Seven participants were based in India, while one was based in Canada and one was based in the United States.

As stated in the researcher's application to the REB, participants had the choice either to send back a scanned version of the consent form or to give verbal consent at the start of the interview. All but one participant chose the second option. Participants also chose whether or not they would be willing to be recorded. It was made clear to them that this was optional, but all agreed. Lastly, participants made a decision as to whether they wished to be identified by name. Although all participants gave permission to be quoted by name, I decided afterwards that it was preferable that they be left anonymous to prevent any risk of unintended consequences on account of the views they chose to express. They are instead referred to as Participant 1, Participant 2, and so on, in chronological order of their interviews. Any identifying information has also been excluded, though some non-specific information is included and the participants' respective gender pronouns have been used. All participants were either DPO representatives or researchers, because no Indian officials responded to requests for interviews.

The interviews consisted of prepared but open-ended questions. Questions mainly focused on areas that my reading of the RPwD Act or the literature review indicated might fail to meet the needs of PwIDs. An effort was made for all questions to be phrased neutrally so as not to predispose respondents toward a certain answer, although sometimes making a question's purpose clear to a participant entailed suggesting possible responses. Because of the large number of topics covered by the RPwD Act (and the shorter length of some interviews), not every participant could be asked each question, though some questions were nonetheless asked several times. Most of the questions fall under one of this study's research questions, although some were on related topics that helped inform the "Discussion" section. Before each interview (except one that occurred on very short notice), a tailored list of questions was prepared for the participant, and these were followed as much as possible, though some follow-up questions were also asked for clarification. Follow-up questions were never used to push back against the comments of participants. In addition, the format of individual interviews as opposed to focus groups allowed each interviewee maximum freedom to express their views.

The interviews were recorded and transcribed. The transcripts are literal as far as possible but have been lightly edited. Out of respect for interviewees for whom English was not a first language, grammar was corrected except in cases where the error is common for native speakers. The transcripts have not been included as appendices, firstly because interviewees were assured the recordings of the interviews would not be widely shared, and secondly because the transcripts collectively span 160 pages in all. Nonetheless, sections of the transcripts are quoted directly in the Results and Discussion chapters. Any remaining errors have been corrected using square brackets where the transcripts are quoted in the research. Unfortunately, for reasons unknown, the recording of Participant 8 only recorded from the researcher's computer and all the participant's valuable remarks were lost. Soon after this came to light, I summarized Participant 8's comments to the best of memory and emailed them to him. He confirmed that they were accurate with one correction, and they have accordingly been cited in the "Results" section.

Assessment Criteria

The “Discussion” chapter opens by judging the adequacy of the RPwD Act’s provisions in the areas of the thesis’ five research questions, breaking the research questions into subtopics where applicable. Each item is given one of the following four rankings for the extent to which it meets the needs of PwIDs: “Fully adequate,” “Mostly adequate,” “Partly adequate,” or “Not adequate.” The rankings are based on two criteria: firstly, meeting the needs identified in the academic and grey literature, and secondly, meeting the needs identified by interview participants.

Positionality

England (1994) famously argued that “fieldwork is intensely personal, in that the positionality [i.e. position based on class, gender, race, etc.] and biography of the researcher plays a central role in the research process, in the field as well as in the final text” [square brackets in original]. The purpose of this section is to reflect on how my positionality played a role in the research. Taking positionality into account is especially important for qualitative research, because the researcher is, in a sense, the measurement instrument (Bourke, 2014). That is, more so than with a quantitative study, deciding which observations merit inclusion in the “Results” section requires the subjective judgement of the researcher. That same subjective judgement remained very important for moving from results to the conclusions found in the “Discussion” section. This subjective judgement introduces space for the researcher’s identities, experiences, and biases to impact the direction of the study.

As a white Westerner without ID, I very likely bring a different perspective to the study than PwIDs in India might have. Although I have some experience with disability-related tasks in a work and volunteer context, this experience is much less than the lived experience of PwIDs or the professional experience of the interview participants. I also have never been to India, meaning my knowledge of the country is entirely second-hand. This manifested itself, for example, when I asked a participant about the needs of adults with ID once their parents were too old to take care of them. I had forgotten that most families in India are multigenerational and that other members of the family thus take care of them. This highlights the value of surveying academic literature published in Indian journals and interviewing subjects based in India.

I also realized a few times in the study that I had unduly taken a response from one participant and used it as part of the premise for a follow-up question in an interview with a subsequent participant. The implicit thinking, I believe, was that in both cases they were broadly speaking part of the Indian disability rights sector, and therefore they would likely have similar perspectives on certain core issues. In one case, however, my assumption elicited the question, “Where did you get that from?”. The question was not accusatory, but rather one of surprise. Experiences such as this reminded me of the diversity of experiences and views that exist within any group of people, even working in the same sector on similar issues.

While I gained many insights about the lived experiences of PwIDs in India through the interview process, my positionality remained important for the writing of the “Results” and “Discussion” sections. The question of insider/outsider status arises, one which becomes highly complex upon examination (Merriam et al., 2001; Bourke, 2014). The most natural interpretation, which I believe holds true to a significant extent, is that as an outsider my understanding will be limited in certain regards and my biases will color those areas. One participant, on the other hand, graciously raised another possibility. When I said I could send him a finished copy of the research, he responded, "I will be very happy. I will be very happy [laughing]. So that I can see the insights of a person from outside [laughing]. Because your perceptions will not be biased. You will be looking at things as they are." While I believe this perspective on the merits of outsider status is too generous, it does open the way for a synthesis discussed by Merriam et al. (2001), which holds that both insider and outsider perspectives can help illuminate a given topic.

I have endeavored to overcome the obstacles posed my status as an outsider while safeguarding the benefits. For example, I have tried to understand the effects of provisions in the RPwD Act such as legal guardianship and inclusive education (discussed below) as they will play out in the Indian context as opposed to in the West, while at the same time trying to learn from the successes and failures of Western experiences of disability in order to bring a valuable comparison to the situation. Nyamnjoh (2012) uses the metaphor of the three blind men examining an elephant and coming to different conclusions based on their position relative to the elephant to illustrate the necessity of bringing together diverse perspectives: "If they were scientists, they might have under-stood that science is a collective pursuit, and that no one has a monopoly on insights and the truth." It is my hope that the social science presented in this paper has benefited from diverse perspectives and come close to an objective depiction of the elephant.

CHAPTER SIX

RESULTS

This chapter integrates the findings that transpired from the synthesis of the existing literature, the analysis of documents, and the in-depth interviews. It begins with a summary of participants' overall perspectives on the RPwD Act. After this, the results of the research are organized according to the order of the thesis' five research questions. Due to the expansive scope of the RPwD Act, a considerable number of issues were analyzed with regards to PwIDs, which led to the emergence of a few sub-topics under some research questions. There is some overlap and interplay between the questions, meaning the responses are not entirely compartmentalized.

Overall Opinions of the Act

Several of those interviewed gave overall opinions on the RPwD Act. They were divided between generally negative views and generally positive views. Participant 1's overall view of the RPwD Act was that "at the outset, for many people, it appears as if there's an improvement [over the PwD Act], but it's not. [The RPwD Act is] more regressive than […] progressive." Likewise, Participant 6 said that "on paper it looks like a good Act, but it really doesn't have any teeth." She argued that a 2012 draft of the Act had been very strong but that by the 2016 version "they actually have diluted most of the proactive provisions we had put in for persons with disabilities." Participant 9 said the RPwD Act would likely not mitigate the problems facing PwIDs by much.

Participant 3 felt the RPwD Act was a good piece of legislation but that implementation would be difficult. She said "the theories are right, the thinking is correct, the attitudes are correct, the need has been identified, but the only thing is getting from the need to practice." Participant 4 said: "There are definitely areas that need improvements, that's with any law which comes, but I think it's a move in a positive direction. If you looked at our previous Act [the PwD Act], versus the new one now, [the RPwD Act is] more inclusive of more disabilities, it's more child-centric. It's trying to unify things for everybody so that you have a single disability card which is useful throughout the country, so it doesn't matter where I migrate." In addition, while Participants 2 and 5 did not give overall opinions of the Act, both supported its provisions in every response they gave.

Despite the diversity of views seen above, most of those interviewed for the research believed that theories aside, putting the RPwD Act into practice would be challenging. The main concern was that adequate policies would not be put in place to implement its provisions. For instance, after stating that the RPwD Act's provision on sexual and reproductive health care was adequate from a legislative perspective, Participant 1 then qualified his remarks: "What are the programs? What are the schemes? And where are they operated? And more than all these things, what are the budgets that you have allocated?". The phrase "the appropriate government shall within the limit of its economic capacity and development" prefaces four different provisions in the RPwD Act (Gazette, 2016). Participant 6 was critical of its inclusion and identified it as part of a wider pattern in the Act in which ideals were included but with wording such that the government would feel no pressure to implement them. This thesis will assess whether the RPwD's provisions are realistic, but the research's scope does not extend to analyzing whether the provisions have so far been implemented.

Research Question #1

Among PwIDs in India, what is the distribution of basic demographic characteristics and severities of ID, and how are these characteristics addressed in the RPwD Act?

This section begins with an exploration of the literature on intersectional prevalence data, in greater depth than would have been possible in the literature review. Next, the relevant sections of the RPwD Act are examined in light of this literature.

Caste and Religion

The 2011 census provides the only available intersectional data on caste and religion among PwIDs. It found a considerably lower rate of ID among STs, but a slightly higher rate among SCs and other religious and ethnic minorities (Centre for Sustainable Use of Natural and Social Resources & Minority Rights Group International, 2019). Sharma and Ramakrishna (2013) report the number of cases of ID by religion, but as they have not provided the statistics for religious affiliation in the sample as a whole, it is impossible to say whether any religious group was disproportionately represented among those with ID. Kashyap et al. (2012) similarly provide a sample broken down by religion, in their case of people certified to have ID, but they likewise fail to state the religious composition of the broader population from which they were drawn.

Gender and Age

Males appear to be disproportionately affected by ID. The 2011 census found 870,708 males with ID compared to 634,916 females, accounting for 58% and 42% of the total, respectively (Office of the Registrar General & Census Commissioner, India, 2013). In the same census, there were 940 females for every 1,000 males in India, which partially but not fully accounts for the gap (Chandramouli, 2011). The study conducted by Sharma and Ramakrishna (2013) found ID was significantly more prevalent among males than females in both rural and urban areas (58% of cases were among males and 42% among females, in both cases—the exact same proportions as the census). As with religious affiliation, this data is difficult to interpret given the article does not give the sex ratio for the sample as a whole (a ratio which varies significantly across India). However, it appears safe to assume the ratio was not as skewed as the dataset, leading to the conclusion that males are disproportionately affected by ID. Data from Kumari et al.'s (2009) study and Girimaji and Srinath's (2010) literature review also show that ID is found disproportionately among males.

Kumari et al. (2009) report that ID occurs disproportionately in younger age groups. Similarly, census data shows the age bracket with the highest rate of ID is 10-to-19-year-olds, and that prevalence declines with each subsequent bracket (except for a slight rise for those aged 90 and above) (Office of the Registrar General & Census Commissioner, India, 2013).

Socioeconomic and Rural/Urban Status

According to the 2011 census, rural areas are disproportionately affected by ID, though somewhat less so than they are disproportionately affected by disability in general (Office of the Registrar General & Census Commissioner, India, 2013). Kashyap et al. (2012) report that among those certified with ID, 50.4% lived in rural areas, 29.2% lived in semi-urban areas, and 20.4% lived in urban areas. A meta-analysis of independent studies likewise suggests ID is more common in rural areas than urban areas, as well as among people of lower socioeconomic status (Girimaji & Kommu, 2016).

Levels of Severity

Sources disagree over the relative prevalence of different severities of ID, though there appears to be consensus that profound ID is the least common. A study in Mangalore, Karnataka state found that of cases of ID, 48% were of mild ID, 29% were of moderate ID, 14% were of severe ID, and 9% were of profound ID (Sharma & Ramakrishna, 2013). The authors also cite an earlier study as showing similar proportions, though my reading of the study suggests it may have included other mental disabilities as well, rendering the results irrelevant (see Kumar et al., 2008a; Kumar et al. 2008b). Kashyap et al. (2012) found in their review of certification documents that 3.8% had borderline intelligence, 24.1% had mild ID, 32.3% had moderate ID, 29.2% had severe ID, and 10.6% had profound ID. By contrast, *JM Rey's IACAPAP e-Textbook of Child and Adolescent Mental Health* provides estimates that 80% of cases of ID are classified as mild, 12% are classified as moderate, 3-4% are classified as severe, and only 1-2% are classified as profound (Ke & Liu, 2019).[13] Srour and Shevell (2014) provide an international estimate with cases somewhat more equally distributed between severities; they write that about two thirds of cases are mild or moderate while about one third are severe or profound.

Intersectionality in the RPwD Act

The RPwD Act contains a number of intersectional provisions, which are especially important in light of the demographic data laid out above. The Act lists the equality of men and women as one of eight guiding principles in its preface (Gazette, 2016). Apart from this women are mentioned explicitly five times in the RPwD Act and gender is mentioned explicitly twice

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[13] These figures do not total 100% (they total 96-98%), suggesting there may be a slight error in the figures. The textbook does not clarify its sources, however, preventing me from verifying this. I have nonetheless included it as any error would be minor and the textbook is well respected.

(not counting references in the Schedule or affirmative action provisions for the central and state advisory boards). Rural areas are mentioned three times (aside from in the membership of advisory boards), urban slums are mentioned once, and poverty alleviation is mentioned once. The references to rural areas and the poor are noteworthy because as seen above these groups are disproportionately affected by ID.

Most of the provisions where marginalized groups are mentioned are general provisions, with the groups added through the words “including” or “especially,” such as “sexual and reproductive healthcare especially for women with disability” (Gazette, 2016). Section 37, clause (b) is somewhat more substantive: it offers people with benchmark disabilities “five per cent reservation in all poverty alleviation and various developmental schemes with priority to women with benchmark disabilities” (Gazette, 2016). On the other hand, SCs and STs are not mentioned anywhere except for reserved seats on central and state advisory boards, even though prevalence of ID among SCs is well above average. PwDs from religious minorities are not mentioned at all. The guidelines for the Act give specific criteria for certifying multiple disability, but as noted in the introduction, multiple disability is beyond the scope of the research (Gazette, 2018).

Research Question #2

What is the nature of the certification process specified by the RPwD Act for PwIDs and how appropriate is it for the needs of PwIDs?

As of 2017, the proportion of PwDs who have been certified with benchmark disability in India is 57.98%, according to the government of India (Department of Empowerment of Persons with Disabilities (Divyangjan), 2018). However, the government’s figure was based on the number of PwDs reported in the 2011 census, whereas the real figure is probably much higher, as discussed in the “Context” chapter. It is therefore likely that only a minority of PwDs are certified and that the majority have no access to disability benefits. Furthermore, Participants 6 and 9 said that the rate of certification was probably much lower for people with “invisible” disabilities such as ID, which are harder to certify.

With the low rate of certification in mind, this section analyzes five elements of the RPwD Act’s certification process for PwIDs: definitions, the screening process, the administrative process, criteria for benchmark disability (perhaps the key element), and criteria for high support needs. It should be mentioned again that disability certificates are highly important for PwDs in India because they are necessary to receive disability benefits, as well as to qualify for certain other opportunities, which are discussed below.

Definition and Classification

The RPwD Act offers a general definition of a PwD: “a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others” (Gazette, 2016). This definition aligns with the biopsychosocial model of disability. Both the Schedule of the RPwD Act and the 2018 guidelines for the Act define ID specifically as “a condition characterized by significant limitation both in intellectual functioning (rasoning [*sic*], learning, problem solving) and in adaptive behaviour which covers a range of every day, social and practical skills” (Gazette, 2016; 2018). In contrast to the definition of disability as a whole, this definition aligns with the medical model of disability.

Under the RPwD Act, there are three recognized levels of disability. The first level is known simply as *disability*, the second is known as *benchmark disability*, and the third is known as *benchmark disability with high support needs* (Balakrishnan et al., 2019). Each person considered for certification is assigned a percentage score based on an assessment by medical professional(s), with 0% indicating no disability and 100% indicating profound disability (Gazette, 2018). Scores above 0% but under 40% qualify one for disability, scores of at least 40% qualify one for benchmark disability. Borderline ID gives a score of 25%, while all four other categories give scores of over 40% (Gazette, 2018). Thus, those with borderline ID are recognized as having disability, and those with mild, moderate, severe, and profound ID are recognized as having benchmark disability. In addition, those who had certificates for ID granted under the PwD Act can continue to use those certificates under the rules for the RPwD Act (Gazette, 2017). A separate scale is used to demonstrate high support needs, and an additional pension is afforded to their caregivers (Gazette, 2019b; 2016).

Screening Mechanism

Children who may have ID are normally referred for testing based on the concerns of parents and teachers or based on developmental delay observed by a pediatrician (Gazette, 2018). Balakrishnan et al. (2019) criticize the lack of a specified screening instrument for use by pediatricians. In addition to referrals, section 17, clause (a) of the RPwD Act obliges the appropriate government (i.e., at the national or state level) and local authorities "to conduct a survey of school going children in every five years for identifying children with disabilities, ascertaining their special needs and the extent to which these are being met" (Gazette, 2016). When asked if once every five years was enough, both Participant 4 and Participant 5 answered that it was. Participant 4 noted that children could also be referred for assessment by their teachers earlier than the five-year survey if they were experiencing significant difficulties. She also said, “considering the population we have [laughing], I’m not even sure if once in five years is going to be technically possible.”

Administrative Process

The guidelines for the RPwD Act stipulate that testing for ID should be performed by a child psychologist or clinical psychologist, after which approval for a medical certificate can be granted by a medical board consisting of four particular medical professionals (Gazette, 2018). When asked whether requiring four professionals to approve certification of ID would slow down the process and thus leave people in need uncertified, neither Participant 3 nor Participant 4 felt so. Participant 4 explained that the assessment could be performed by “one or two experts in the field” and that the larger board is only needed briefly to approve the assessment. She did say the present system was not ideal for rural locations and that for those locations it would be helpful if the experts could simply report their results on a monthly or quarterly basis.

By contrast, Balakrishnan et al. (2019) are critical of the centralized certification process for PwDs in the RPwD Act, saying this will reduce the number of people able to be certified. This process contrasts with the process stipulated in a 2009 amendment to the rules for the PwD Act, which made certification possible by only a single professional except in cases of multiple disability by removing the requirement for a medical board (Chavan & Rozatkar, 2014). Participant 6 was likewise critical of the complexity of the certification process. In this vein, Friedner et al. (2018) refer to the certification process for disability as “elaborate (but not fool-proof).” Participant 1 expressed concern that certification is extremely difficult in rural areas due to a shortage of professionals there. Participants 1 and 6 both identified the problem of finding enough professionals as symptomatic of the larger problem of medical definitions for certification, however.

Criteria for Benchmark Disability

The 2018 guidelines for the RPwD Act stipulate that the presence of ID should be identified by two test results: a social quotient (SQ) for adaptive functioning and IQ for intellectual ability (Gazette, 2018; Kishore et al., 2019).[14] If an individual is judged to be impaired in these regards (having scores of less than 85 on both tests), the severity of disability is then judged based on the SQ; the individual's ID is accordingly judged as borderline (70-84), mild (55-69), moderate (36-54), severe (21-35), or profound (0-20). This system is at variance with the standard international definition noted above, according to which cases are stratified into severities with IQ scores. John et al. (2018) state that the SQ scores are used incorrectly in the guidelines, in particular that they should have been compared to the age of the person being tested. More controversially, though, both IQ and SQ tests represent medical criteria. That is, they both align with the medical model of disability by measuring disability purely as a function of the individual, not as the result of an interaction between the individual and the environment. There was a split among respondents as to the relative merits of medical and social criteria, with some participants supporting the use of only medical criteria, some supporting the use of only social criteria, and others favoring a combination of both.

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[14] The guidelines specify that the Vineland Social Maturity Scale (VSMS) should be used to measure SQ. One of two IQ tests should be used: the Binet-Kamat Test of Intelligence (BKT) or the Malin's Intelligence Scale for Indian Children Developmental Screening Test (MISIC) (Gazette, 2018; Kishore et al., 2019).

Support for medical criteria. Three participants supported the use of only medical criteria for certification. Participant 2 said only medical criteria could adequately quantify disability so as to provide disability certificates. A similar position was taken by Participant 5, who said medical criteria were more objective and expressed concern that use of social criteria in India at this time would thus cause some PwDs to not be certified and some people without disabilities to be certified. He did, however, say that development of new criteria that could accurately incorporate social factors such as accessibility was currently ongoing. Participant 8 explained in an email after his interview that based on his experience in the area, ID should be identified with SQ and developmental quotient (DQ), not IQ and SQ. DQ is a measure widely used to quantify ID in children in India, including at the National Institute for the Empowerment of Persons with Intellectual Disability (Persha et al., 2007).[15] Using SQ and DQ would nevertheless mean using medical, not social, criteria.

Support for social criteria. On the other hand, Participant 1 called for completely removing medical criteria from the certification process for disability, and for using questions based on what accommodations the person needs in order to perform better. Participant 6 did not explicitly reject the inclusion of any medical criteria, but she said her main criticism of disability certification in India was that is currently “a very, very, very medicalized process.” She was particularly critical of the short time for which the medical board is with a PwD before they decide on certification as well as the decontextualized certification which ignores the social background and location of the PwD. Participant 9 criticized the use of the medical model for

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[15] DQ is measured with a psychometric instrument called the Developmental Screening Test (DST).

disability certification. She noted the approach of the Washington Group for Disability Statistics (which is based on the social model of disability) as valuable for epidemiology but was skeptical that it would be adequate for certification, saying that there was instead a need to "invent a whole new system for certification." She said that many of the doctors tasked with certification are largely unfamiliar with the topic of disability. Both Participant 1 and Participant 9 blamed the number of uncertified PwIDs on the use of medical criteria.

Support for mixed criteria. Two respondents supported a mixed approach featuring both medical and social criteria for certification. Participant 3 said both medical and social criteria were necessary but that she would focus more on the social criteria as they take into account "the family, the community, the neighbors […] the attitudes of people there […] their understanding […] [and] how religion—the Hindu religion—impacts the path of intellectual disability." John et al. (2018) criticize the 2018 guidelines for identifying ID based on IQ and SQ but not also clinical assessment. In this vein, Participant 4 said it was important to also have "inputs from various stakeholders dealing with the child; if the child is school-going that includes the teachers, it includes a peer review. So it's a very holistic […] assessment which is required." She noted that this information could be instrumental in distinguishing between a case of ID and a case of SLD, for example. She did not, however, discount the importance of medical criteria, and noted that the range of specialists available at her tertiary care centre is not available in much in India.

Criteria for High Support Needs

The board that certifies somebody as having high support needs consists of nine professionals (Gazette, 2019b). To qualify for benchmark disability with high support needs, a person must score at least 60 out of 100 on a complex scale incorporating the score from above and other criteria, particularly being unable to perform daily tasks without assistance (Gazette, 2019b). Unlike the criteria for benchmark disability, the criteria for high support needs do include social criteria, namely "environmental barriers like access to health care or support systems for rehabilitation or health needs" and "socio-economic status" (the latter established by the poverty line) (Gazette, 2019b). However, these two social criteria are worth only 5 points each.

Participants 1 and 4 both criticized aspects of the criteria for the certification of high support needs. Participant 1 argued that the criteria reflect a "class attitude"; he said criteria such as whether the PwD can brush their teeth without assistance reflect a vision of more affluent people in India that fails to take into account the lack of resources found in the low-income communities into which some PwDs are born. Instead of being based on this highly specific vision, he said, the criteria should have been based more generally on health and hygiene. For her part, Participant 4 was concerned about the lack of detail in the criteria. She said the process was well specified from an administrative perspective, for instance setting out the composition of the board for certification, but that the vague assessment criteria left too much discretion to individual professionals.

Research Question #3

What kinds of needs of PwIDs must be met in order for them to have dignity and equality, and to what extent are these needs adequately addressed by the RPwD Act?

Six themes emerged in connection with the dignity and equality of PwIDs: discrimination, awareness, confinement to institutions, privacy, research on PwDs, and disability-selective abortion.

Non-discrimination

Section 3 of the RPwD Act lays out the Act's core provisions on equality and non-discrimination (Gazette, 2016). Subsection 3 is arguably the most essential subsection within section 3, and reads as follows: "No person with disability shall be discriminated [against] on the ground of disability, unless it is shown that the impugned act or omission is a proportionate means of achieving a legitimate aim" (Gazette, 2016). The acceptance of discrimination if it is "a proportionate means of achieving a legitimate aim" has been strongly criticized. The National CRPD Coalition-India (2019), an umbrella organization of Indian DPOs, is critical of the non-discrimination clause including a "qualifier." Participant 7 said that the provision is highly unusual by international standards and that to her knowledge few countries allow for discrimination against PwDs in such a direct way. A systematic comparison of how the RPwD Act compares to the laws of other countries is well beyond the scope of this thesis, however.

On the other hand, Participant 5 defended the wording of subsection 3: "… that is not a rule, that is not a norm, it is only an exception. […] Otherwise […] nobody can discriminate against persons with disabilities. If anybody does that, they can be prosecuted." He gave the example that a person's disability could cause them to behave disruptively and prevent a social function from taking place, saying in such a scenario it would be necessary to discriminate by removing them.

Other provisions on non-discrimination in the RPwD Act include section 20, which sets out the principle of non-discrimination in employment and calls for reasonable accommodation (Gazette, 2016). Reasonable accommodation is another element of the RPwD Act that could potentially be used to allow for discrimination, however. Participant 7 identified undue hardship provisions as a common loophole in laws of other countries whose stated purpose is to forbid discrimination based on disability. Section 2, clause (y) of the RPwD Act defines *reasonable accommodation* as "necessary and appropriate modification and adjustments, without imposing a disproportionate or undue burden in a particular case, to ensure to persons with disabilities the enjoyment or exercise of rights equally with others" (Gazette, 2016).

Awareness Campaigns

As the literature review revealed, social attitudes toward ID in India are often highly misinformed, leading to harmful parental practices, discrimination, stigma, and segregation. In response, section 39 of the RPwD Act requires the government to "conduct, encourage, support or promote awareness campaigns and sensitization programmes" on disability (Gazette, 2016). Awareness is also mentioned in a few other sections of the Act. On the other hand, Participant 1 remarked that the medical definitions of disabilities found in the RPwD Act present a major obstacle to removing archaic attitudes and stereotypes about PwDs among the public.

The question also arises of which group(s) of people most need to be targeted by awareness campaigns and programs. Participants 6 and 9 both felt that awareness campaigns should be targeted at service providers (including health care professionals and teachers) first and foremost, as well as the families of people with disabilities. Regarding families, Participant 3 noted that they need to be made aware that ID is not the fault of the mother, who is often unfairly blamed. Among service providers, Participant 9 highlighted health care providers as most important. Participant 6 also noted the importance of awareness for PwIDs themselves. Although both were critics of a purely medical model of disability, neither emphasized sensitization of the public at large as a priority. Section 39 of the RPwD Act offers six specific goals for the awareness campaigns and sensitization programs it mandates, including fostering "respect for the decisions made by persons with disabilities on all matters related to family life, relationships, [and] bearing and raising children," as well as initiatives "at the school, college, University and professional training level" and for "employers, administrators, and coworkers" (Gazette, 2016). The wording of the section leaves it unclear whether the general population will be a target for awareness-raising efforts.

Institutionalization

Participant 7 noted that institutionalization is one of the main issues facing PwIDs around the world. This has already been noted with reference to India in the literature review, but another participant's descriptions deserve mention. Participant 9 said of institutions in India: "the extent of violence, sexual abuse, […] amounting to torture and cruelty, perpetrated against particularly children with ID in some of these institutions. It's horrendous. I mean, it's like something unimaginable." To make this clear she gave a poignant example from her own work: "… we met this lady who just walked into our counselling centre. And we were talking to her, and […] she started to cry and […] she had a little pouch with a number of hair things, you know, rubber bands, and little, you know, little things she could put in her hair, and stuff like that, but […] her hair was completely shorn off, and so we expressed curiosity and she started to weep. And then she said that, you know, the attendants at the hospital slapped her around, they restrained her hands, and then they chopped off her very long hair which she was very fond of." Participant 9 said she believed families were forced to send their children with ID to institutions by a lack of resources, and also that today's institutions exist because the government has failed to provide community-based alternatives.

Section 5 of the RPwD Act sets out that PwDs "have the right to live in the community" (Gazette, 2016). The Act fails to more specifically prohibit involuntary confinement to institutions, however. Moreover, Chapter IX regulates the registration of institutions for PwDs, but it specifies administrative procedures for granting and revoking registration rather than the conditions for PwDs entering and being discharged from the institutions (Gazette, 2016). Rules for living conditions inside institutions are left to state governments by section 101, subsection 2, clause (d) (Gazette, 2016). Section 15, subsection 2 of the RPwD Act is notable, as it grants PwDs living in institutions the right to "suitable support arrangements to exercise legal capacity" (Gazette, 2016).

Privacy

Privacy is mentioned only once in the RPwD Act, in section 13, subsection 5 (Gazette, 2016). The Act states: "Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy" (Gazette, 2016). Participant 6 said this provision was to ensure that PwDs were given a choice, for instance about when and what they ate, and that "privacy is even more important, especially about toileting and taking a bath or changing your clothes, where often in a room full of people, even adults with disabilities—intellectual impairments or very severe disabilities—are stripped of their clothes and dressed in fresh clothes, with no regard to their dignity."

An issue with the RPwD Act's provision on privacy, however, is that privacy is guaranteed only from those providing support to PwDs, whereas people in general are not required to respect the privacy of PwDs (National CRPD Coalition-India, 2019). As discussed in the literature review, privacy should also have been mandated in the area of accessing disability benefits. As Mishra et al. (2012) observed, a separate document should have been issued with less personal information for accessing benefits. Currently, under the rules for the RPwD Act, the disability certificate for ID (Form VII) continues to include personal information such as the person's address and details about the type and severity of the disability (Gazette, 2017).

Participants 1, 2, and 4 all felt that the existing situation with the disability certificates does not violate the privacy of PwIDs and that the system in place is necessary to identify those deserving benefits. Participant 4 said the amount of information needed to receive benefits by means of a disability certificate is no greater than the amount of information needed to receive benefits in India using a social security card. Participant 7, on the other hand, said requiring PwDs to disclose important personal information to receive benefits did violate their privacy. She argued that PwDs should only be required to show documentation from a doctor saying they are eligible for a particular benefit, not the details of which type of disability they have.

Research on PwIDs

The need for research involving PwIDs to be ethical has been highlighted by Chavan and Rozatkar (2014) in their literature review. Participant 6 expressed concern about a large amount of "medical research, a lot of, you know, psychosocial research that was going on, using disabled people as guinea pigs." The topic of research on PwDs has been addressed by the RPwD Act. Section 6, subsection 2 states that before any PwD is the subject of research, their free and informed consent must be acquired and approval must be secured from a Committee for Research on Disability (Gazette, 2016). Section 4 of the 2017 Rules for the Act gives details on the composition of the committee.

Disability-selective Abortion

The right to motherhood of women with ID will be discussed below, but a separate question concerns cases in which a mother (with or without disability) is found to be pregnant with a fetus with a disability. In particular, the question of whether it is ethical, or should be legal, to induce an abortion because the fetus has a disability has been controversial. Participant 9 noted that this question is difficult because of the tension between the rights of the mother and the rights of the child. She further said that the stance of India's DRM has been that disability-selective abortion should not be permitted.

Research Question #4

What is the nature of the needs of PwIDs with regards to legal guardianship, and to what extent are these needs adequately addressed by the RPwD Act?

Guardianship in the RPwD Act

Perhaps the most controversial topic during the drafting of the RPwD Act was legal guardianship for PwDs (Friedner et al., 2018). Two sets of activists lobbied the government with opposite goals during the drafting of the law (Friedner et al., 2018). On one side were people with visual disabilities, hearing disabilities, locomotor disabilities, and psychosocial disabilities, who wanted full legal capacity for themselves as was stipulated by the UNCRPD, while on the other side were parents of PwIDs and ASDs, who feared their children would be left vulnerable to manipulation if full legal capacity were granted and thus wanted guardianship over them

(Friedner et al., 2018). The latter group of activists are represented by the organization Parivaar, India's federation of parents of people with intellectual and developmental disabilities. Thus, parents of PwIDs and ASDs had hoped for plenary guardianship, while other PwDs had hoped guardianship would be completely removed; the final result was in effect a compromise (Friedner et al., 2018).

The RPwD Act states in section 13, subsection 2 that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law" (Gazette, 2016). Crucially, though, section 14, subsection 1 goes on to stipulate that if in the judgment of a court a PwD "is unable to take legally binding decisions," the PwD "may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person" (Gazette, 2016). The legal capacity of PwDs is thus rendered conditional. It should be noted that in the context of the above provision "limited" means for a set length of time only (Gazette, 2016). The section continues, however, that if the limited guardianship needs to be instated repeatedly or if greater assistance is deemed necessary, the court may "grant total support" to the PwD (Gazette, 2016). "Total support" refers to a permanent guardianship arrangement, which is known as *plenary guardianship*. Subsection 2 affirms that anyone deemed a guardian under previous legislation shall remain a guardian under the RPwD Act (Gazette, 2016).

The administrative details of the appointment of a guardian are not specified by the RPwD Act. A set of procedures does, however, remain in force in the NT Act (passed in 1999) (National CRPD Coalition-India, 2019). These procedures include specifications for the local-level committees that appoint guardians, how guardians are appointed, the duties of guardians, reporting requirements, and conditions for removing guardians who misuse their position (Gazette of India, 1999). Importantly, the NT Act includes plenary guardianship rather than limited guardianship and thus stands in contradiction to the RPwD Act (National CRPD Coalition-India, 2019). The NT Act's provisions for removing guardians when necessary are supplemented by section 14, subsection 3 of the RPwD Act, which states that if a PwD is "aggrieved by the decision of the designated authority appointing a legal guardian," they may "prefer an appeal" to an authority appointed for that purpose (Gazette, 2016).

Views on the Guardianship Provisions

Eight of nine participants interviewed for this thesis were asked their opinion on the RPwD Act's provisions for legal guardianship. They were evenly split between support and opposition. The remainder of this subsection has three goals: first, to explain the reasons that were given in support of the limited guardianship provisions; second, to explain the reasons given in opposition to the provisions; and third, to examine the alternative to legal guardianship that has been proposed.

Arguments in support of guardianship. The core of the case for including provisions for legal guardianship is the idea that certain individuals lack the mental capacity to make good decisions in their own interest. Participant 2 presented such an argument: "I think there has to be some provision regarding guardianship, because there are some persons who do not have the capability, who do not have the capacity to perform the required acts due to the impairment of their mental functioning." Participant 5 noted that the issue of guardianship versus legal capacity was debatable because it strikes at the foundation of rights-based ethics; his view was that rights can only be granted to persons with the capacity to make decisions "proper and correct to the interests of the person." Participant 3 explained that when she was on a guardianship committee (some time ago) they would interview the person with ID and if the person was unable to answer simple questions this would indicate the disability was severe enough that guardianship was necessary. The issue of mental capacity becomes more acute when the person with ID has inherited property, which other people may naturally wish to acquire for themselves. Participant 5 expressed this concern as follows: "if the child [who inherits property] […] has his rights and there is no guardianship, then maybe some unscrupulous people can manipulate and deceive [him]. That's why [legal guardianship] is there […] for the benefit of people with intellectual disability."

Participants 2 and 5 noted that guardianship was not necessary for most PwDs and that the RPwD Act did not require it to be implemented except where necessary. Participant 5 also emphasized that if a person no longer needed a guardian, they could end the guardianship. For cases in which somebody had to be trusted to protect the interests of a PwD, however, Participant 5 argued it should be their family, who care most about their wellbeing. Participant 2 acknowledged that the guardianship provisions could be abused by guardians in certain cases but said a provision along these lines could not be dispensed with and noted that the law contained safeguards against such abuses (referring to the aforementioned appeal mechanism for challenging the guardianship). Participant 3 said that in her time on the guardianship committee, only one case came to their attention in which a guardian worked against the interests of the person with ID, seeking to gain possession of their property, and that the guardianship committee prevented this and arranged for the PwD to lease their property to the guardian. She explained that the committee asked various questions to caregivers (as well as the PwIDs) to ensure that

PwIDs would be properly cared for. Furthermore, she stated that people of low socioeconomic status benefitted the most from legal guardianship.

While Participant 8 supported the existence of guardianship, he did recommend a change to the administrative process for granting it. Based on his fieldwork he felt that the district magistrate, who is one of the three members of the local level committee that grants legal guardianship under the NT Act, should be replaced by a lower-ranking official so that he or she would have time to review applications in more depth.

Arguments against guardianship. In contrast to Participants 2 and 5, Participant 6 criticized “the cultural belief that people with intellectual impairments are not capable of making decisions for themselves, which can range from very small decisions, of ‘what I want to eat’ to big decisions of ‘where I want to live’ and ‘where I want to put my money’.” Also, Participant 6 said that Parivaar, the main backer of legal guardianship in the RPwD Act, is mainly composed of middle-class families, not the poor. Because they are more affluent, she argued, they are concerned about their property being well taken care of after they die, and hence in guardianship for their children with ID.

While guardianship is intended to prevent the person with ID’s property from being misappropriated, concerns have been raised that it will in fact be used by the guardian to legally take the property away from the person with ID. Participant 9 said this happens very often and estimated that 20-30% of people in institutions were there as a result of legal guardianship being invoked in property disputes. Institutions have already been discussed above. The Bapu Trust, a DPO, has also reported the tragic case of a woman with ID named Bula (National CRPD Coalition-India, 2019). Bula inherited part of a house and a sum of money but her husband used the guardianship provisions of the RPwD Act to gain control of her property, after which she disappeared and has not been seen again (National CRPD Coalition-India, 2019). Participant 9 said abuses of guardianship in India were especially likely to take place without consequences because the process for appointing a guardian was "a routine administrative matter" and second and third reviews of a guardianship arrangement virtually never occurred in practice. She identified the guardianship provisions as part of a widespread pattern of incapacity laws dating to the colonial era. Also, while Participant 8 had suggested a lower-level official than the district magistrate be tasked with granting guardianship, Participant 9 said the district magistrate was in fact an official at too low of a level. Asked about the risk of a person with ID being manipulated without the protection of guardianship, she estimated the risk was "doubled or tripled under the guardianship regime."

Between the manipulative guardians described by Participant 9 who send PwIDs to institutions and the fully benevolent guardians described by Participant 5 there are intermediate cases who take care of the child but infringe on certain rights. Participant 1 argued that families often use the power of guardianship to act in their own interests rather than those of the PwD by seeking abortion or sterilization for women with disabilities against their will. Forced abortions and sterilizations will be discussed further in a later section.

The alternative to guardianship. Participant 6 clarified that none of those opposed to the guardianship provisions of the RPwD Act were proposing a system of unaided decision-making for PwIDs. Rather, Participants 6, 7, and 9 all said they favored a system of assisted decision-making where the person with ID would have a support network to counsel them but ultimately make their own decision. Inclusion International (2014) agrees with this approach, arguing that it upholds the "right to decide" of PwIDs, unlike substitute decision-making as enabled by legal guardianship.

While Participant 6 said India needed to work toward establishing a full system of assisted decision-making, she said that the country was not ready yet. She noted that in India, regardless of whether guardianship formally exists, PwDs will not have much freedom to set the course of their lives. In this vein, Participant 7 said assisted decision-making in India required a significant shift in cultural attitudes toward ID. She said at a lower level some local branches of Parivaar were beginning the transition toward assisted decision-making by encouraging caregivers to allow PwIDs to express preferences in smaller matters such as what they eat and where they want to live, before moving toward more difficult matters like contracts.

Research Question #5

What is the nature of the health, education, and employment needs of PwIDs and to what extent are these needs adequately addressed by the RPwD Act?

This section is divided into four sub-sections. The first three cover the health, education, and employment of PwIDs, while the fourth covers reproductive health and education, which were more easily discussed in their own section.

Health

Based on my reading of the RPwD Act, the three main health-related topics it covers (aside from reproductive health, to be discussed below) are health care, rehabilitation, and prevention. Section 25, subsection 1 of the RPwD Act contains the Act's key provisions on health care. These are highly ambitious, including "free health care in the vicinity specially [*sic*] in rural area subject to such family income as may be notified" and "priority in attendance in treatment" (Gazette, 2016). Subsection 2 goes on to require the government to take prevention measures to reduce the incidence of disabilities (Gazette, 2016). Section 27 of the Act requires national and state governments to provide PwDs with "services and programmes of rehabilitation, particularly in the areas of health, education and employment," adding the condition "within their economic capacity and development" (Gazette, 2016). Participant 8, an expert in the area, affirmed that these three areas are the most central issues for the health of PwIDs.

Education

Section 31, subsection 1 of the RPwD Act mandates education for children with benchmark disabilities up to the age of 18 (Gazette, 2016). Section 32, subsection 1 of RPwD Act also includes a 5% reservation in spaces for enrollment at institutions of higher education that are run by or receiving funding from the government (Gazette, 2016). Subsection 2 goes on to specify that such institutions must increase their upper age limit by 5 years for people with benchmark disabilities (Gazette, 2016). Furthermore, the RPwD Act includes provisions specifically aimed at the education and training of PwIDs. Section 17, clause (c) of the RPwD Act stipulates that the appropriate government and local authorities must "train and employ teachers, including teachers […] who are trained in teaching children with intellectual disability" (Gazette, 2016). Section 19, subsection 2, clause (c) mandates "exclusive skill training programs […] for those with developmental, intellectual, multiple disabilities and autism" (Gazette, 2016).

Section 16 of the RPwD Act calls for schools to "provide inclusive education to the children with disabilities" and clause (iv) of that section clarifies that this includes providing "necessary support individualised or otherwise in environments that maximize academic and social development" in a way that is "consistent with the goal of *full inclusion* [emphasis added]" (Gazette, 2016). On the other hand, section 31, subsection 1 grants each child with a benchmark disability from the age of 6 to the age of 18 "the right to free education in a neighbourhood school, or in a special school, of his choice" (Gazette, 2016). Thus, the RPwD Act appears to allow for choice between inclusive education and special education, with the goal of eventually moving toward a system of entirely inclusive education. Eight interview participants were asked about the relative merits of inclusive and special education. Five of eight said inclusive education was best for PwIDs, and two more said that those with milder cases of ID should receive inclusive education. None criticized inclusive education in principle.

Participants 1 and 8 said that children with ID would benefit in terms of their social development from being in an inclusive setting. Participant 1 said that even if some of those with ID do not learn everything in the curriculum, they will learn "how you get to know the various spaces in which you articulate yourself, and you would realize your identities, and [receive] the peer support that helps children with disabilities to cope with the curriculum," benefits he felt were more important than academic knowledge. Participant 8 also noted that special schools are not available in rural areas or for the poor and that inclusive education is therefore often the only alternative to children being left at home alone. He observed in his fieldwork that the children with ID were very happy when they could spend the day around other children.

In order to bring about full inclusion for children with ID in a regular school, respondents noted several changes that needed to be made. Participant 7 emphasized "the transformational work of changing the way the classroom works: making sure there's peer support, making sure the curriculum is adapted, making sure that teachers have a range of teaching skills for different learning needs." A "range of different learning styles and needs" is not something limited to PwDs, she noted. An example of adapting the curriculum suggested by Participant 4 was including vocational classes from a younger age for students with disabilities who will likely go into vocational training after Grade 10 based on their intellectual capacity. Participant 1 also noted that modified assessment patterns may be needed. Participant 3 said the government of India has tried adding support teachers who work with children ID in an inclusive classroom, but she expressed doubt that it was working. Participant 7 also opposed such a system, saying the support staff should be attached to the classroom as a whole to make the curriculum more inclusive, rather than directly to the child with ID; giving the child his or her own support person, she said, inadvertently causes a situation in which the child "continues to be segregated within the classroom." She made the more general point that failures of inclusive education were not due to too much inclusion, but to insufficient resources dedicated to it—that is, to too little inclusion.

While all participants agreed inclusion was good in principle, some noted obstacles to its implementation. Participant 4, who supported inclusive education for all students with ID, nevertheless expressed doubt that India was ready for it yet. "So inclusion, I firmly think, should be there. At this present moment, are we ready for it? I don't think so," she said, and explained that the appropriate infrastructure and educational resources needed to be put in place for children to properly benefit from inclusive education. For her part, Participant 3 expressed her concerns about inclusive education through the rhetorical question, "inclusion doesn't stop at the gates of the school, right?"; she said admission to a regular classroom was not enough, and that children with ID needed to experience acceptance once they were admitted. She noted that India has very large class sizes and that children with ID cannot receive much teacher attention, and that parents of children with ID in inclusive education therefore come to her saying they want to put them in special education. Participant 5 noted that while India had had inclusive education, including for children with ID, “unfortunately, [more recently] the system has been set up in such a way that we have copied the West” and that this had led to the cultural belief in India that children with intellectual disabilities should go to special schools.

Participants 1 and 7 both mentioned that research on inclusive education had found it to be more beneficial than special education. As seen in the literature review, literature from India has only shown success for inclusive education of PwIDs where the severities are mild or moderate, not where they are severe or profound. On the other hand, Inclusion International (2018), the global organization representing PwIDs, has defended inclusive education for all children with ID and states that resistance to inclusive education is based on “myths and misconceptions.” Studies from India reflect current conditions in India, but given the RPwD Act has stipulated an eventual goal of “full inclusion,” it is worthwhile to also consult international literature on inclusive education to see what goals might be achieved.

The international literature finds that inclusive education produces either better results or the same results as special education for people with all severities of ID. A study on children with ID (with IQs ranging from 40 to 75, i.e. mild and moderate ID) in special and inclusive education programs in Switzerland over two school years found that improvements in literacy were significantly better (though only slightly) in inclusive settings, while no significant differences were found in changes to mathematical ability or adaptive behavior (Sermier

Dessemontet, Bless, & Morin, 2012). The authors also review past literature and find either better outcomes from inclusive education or no difference but note that many researchers did not match the children in the two systems for ability at the start of their studies, potentially confounding the results (Sermier Dessemontet et al., 2012). Two studies were on children with severe ID, with one finding no significant difference in results between inclusive and special education and one finding significantly better adaptive functioning for children in inclusive education (Sermier Dessemontet et al., 2012). More recently, Szumski and Karwowski (2014) conducted a study on children with mild ID in special, integrative, and mainstream schools (the latter two types being examples of inclusive education) in Poland. They found that the students with mild ID in inclusive schools outperformed their counterparts in special schools but that those in special schools were higher in social integration.

Employment

Chapter IV (sections 19-23) of the RPwD Act contains the main provisions to support the employment of PwDs in India, including skills training, non-discrimination (discussed above), and a requirement for enterprises to maintain equal opportunity policies (Gazette, 2016).

Chapter VI arguably holds the most important provision for employment, however. Under the PwD Act, 3% of government jobs were reserved for PwDs, including 1% each for people with visual, hearing, and locomotor disability, but none for mental disability (Friedner et al., 2018). Section 34 of the RPwD Act, subsection 1, clauses (d) and (e) list people with benchmark disabilities in the categories of “autism, intellectual disability, specific learning disability and mental illness” together with multiple disability as together being entitled to 1% of government job positions (Gazette, 2016). The three previously existing categories—people with visual, hearing, and locomotor disability—are likewise entitled to 1% each, leading to a total of 4%. These employment reservations have been described by Friedner et al. (2018) as the most important provision in the RPwD Act. When compared to the reservations in the PwD Act, they appear to represent a momentous development for PwIDs.

The system of reservations has not been universally positively received, however. During the drafting of the RPwD Act, there was considerable contestation over which groups of people with disabilities would have access to what share of employment reservations (Friedner et al., 2018). The question arises whether a 1% reservation for ID, ASDs, SLD, psychosocial disability, and multiple disability all together is adequate. When asked about this, Participant 6 argued that if it is implemented it would still represent a great step forward. She noted that reliable data on the relative prevalence of different types of disabilities does not exist, making it difficult to conclude that the proportions are unjust. Furthermore, she pointed out that the category of locomotor disability also includes a range of different conditions. The category of which ID is a part is not necessarily "bigger" than the others, therefore. On the other hand, Participant 7 predicted that because ID is grouped with several other disabilities, people with milder forms of disability such as a mild ASD or mild psychosocial disability would ultimately take almost all of the 1% from which PwIDs are supposed to receive their share.

Another concern of Participants 6, 7, and 9 was that even with reserved spaces in government posts, PwIDs would be type-cast into certain jobs. Participant 6, for example, said a 1% reservation for the above-mentioned categories would be a great step forward, but was worried about "the mindset that says that these people are good for only very low-skilled kinds of jobs." Section 33 of the RPwD Act requires "an expert committee with representation of persons with benchmark disabilities” to “identify posts in the [government] establishments which can be held by respective categor[ies] of persons with benchmark disabilities” (Gazette, 2016).

With all these problems considered, the question arises whether setting quotas is a useful approach at all. Participants 7 and 9 were both conflicted over this question because they felt quota systems were difficult to implement. Participant 7 said awareness could be the “key ingredient” in allowing PwIDs to succeed in the workforce, provided that this was not just job readiness programs for the PwIDs themselves but also sensitization programs for the coworkers of PwIDs. She noted that efforts to increase awareness are compatible with a quota system such as the employment reservations found in the RPwD Act. As noted above, the RPwD Act does include a requirement for sensitization programs in the field of employment, specifically for “employers, administrators, and coworkers” (Gazette, 2016).

In addition to requiring the government to reserve spaces for PwDs, the RPwD Act requires “the appropriate Government and the local authorities” to “provide incentives to employer[s] in [the] private sector to ensure that at least five per cent of their work force is composed of persons with benchmark disability” (Gazette, 2016). It is qualified, however, by the phrase “within the limit of their economic capacity and development” (Gazette, 2016). As noted above, Participant 6 said this phrase allows the government not to take any action wherever it is included.

Reproductive Health and Education

Reproductive rights are important for PwDs as for other people. Participant 7 noted that the reproductive rights of PwIDs is an issue that becomes especially important for women with ID. The RPwD Act states that the appropriate government must provide “sexual and reproductive healthcare especially for women with disability" in section 25, subsection 2, clause (k) (Gazette, 2016). Participant 1 found no flaw in this provision, only stating that implementation was poor.

The Women with Disabilities India Network (2019) reports that women with ID and psychosocial disability are especially likely to be deprived of the right to choose whether to have a sterilization or abortion; these are often forced upon them. Participant 3 was skeptical that forced sterilizations posed a major problem, saying they were "not very common […] definitely not." On the other hand, Participant 9, while acknowledging that data on the topic were scarce, said it was "kind of [an] in-the-closet kind of thing. But, you talk to any service provider, they tell you that families, you know, they just do it [forced sterilizations] as a matter of routine." Section 10, subsection 2 of the RPwD Act states, "No person with disability shall be subject to any medical procedure which leads to infertility without his free and informed consent" (Gazette, 2016). This provision clearly outlaws forced sterilization. Abortion has long been forbidden, including for women with disabilities, by the Medical Termination of Pregnancy Act, 1971 (Gazette of India, 1971). The issue is complicated, however, as Participant 1 pointed out, by the fact those forcing the sterilizations or abortions are often the legal guardians of the person with ID. The RPwD Act in fact facilitates abortions under such circumstances; section 92, clause (f) removes the need for a woman's consent for an abortion in cases where she has a severe disability and the guardian consents (Gazette, 2016). The provisions for legal guardianship, already discussed above, thus become paramount for understanding reproductive rights under the RPwD Act.

Participant 1 stated that reproductive health measures for PwDs must be supported by reproductive education. Girls with ID and some other disabilities are often not given such education, however, because they are erroneously assumed to be asexual (Women with Disabilities India Network, 2019). The RPwD Act partially addresses this problem, guaranteeing that PwDs must "have access to appropriate information regarding reproductive and family planning" (Gazette, 2016). Participants 6 and 7 both said further details were needed for this provision to be effective, but both also said these did not need to be included in the legislation itself. Participant 6 said clarification should have been included in the 2017 Rules for the RPwD Act. This information being accessible, though, is not equivalent to it being included in the curriculum. Participant 7 noted that the information on reproductive and family planning should be available in a format accessible to PwIDs in schools, to the same extent that it should be accessible to students without ID.

CHAPTER SEVEN

DISCUSSION

This chapter discusses the results from the previous chapter. It begins with overall conclusions on the adequacy of the RPwD Act in meeting the needs of PwIDs, continues with discussion of the results in the order of the study's research questions, and concludes by noting some limitations of the study design.

Overall Conclusions

The findings of this study show that despite its progressive appearance and wide scope, the Rights of Persons with Disabilities Act, 2016, together with its associated rules and guidelines, only partially meets the needs of PwIDs in India. The Act does not fully address the areas of any of the thesis' five research questions. It does contain commendable provisions on many topics, such as measures to protect PwDs from unwanted research and its provisions on education. Nonetheless, there are still significant shortcomings; as a whole the RPwD Act is inadequate in a range of ways and will help perpetuate negative life outcomes for PwIDs. Table 1 summarizes the extent to which the provisions in the RPwD Act meet the needs of PwIDs in the areas corresponding to the research objectives of this study.

Table 1

Adequacy of the Provisions of the RPwD Act by Research Question

Research Question Number and Topic	**Adequacy of Provisions**	**Sub-topic**	**Adequacy of Provisions**
RQ #1: demographics	Partly adequate	N/A	
RQ #2: certification	Not adequate	Definitions	Not adequate
		Screening	Partly adequate
		Certification process	Not adequate
		Criteria for disability	Not adequate

		Criteria for high support needs	Not adequate
RQ #3: dignity and equality	Partly adequate	Non-discrimination	Not adequate
		Privacy	Partly adequate
		Institutionalization	Not adequate
		Awareness campaigns	Partly adequate
		Research on PwDs	Fully adequate
		Disability-selective abortion	Not adequate
RQ #4: guardianship	Not adequate	N/A	
RQ #5: health, education, and employment	Mostly adequate	Health	Mostly adequate
		Education	Fully adequate
		Employment	Mostly adequate
		Reproductive health and education	Partly adequate

Research Question #1

Among PwIDs in India, what is the distribution of basic demographic characteristics and severities of ID, and how are these characteristics addressed in the RPwD Act?

Interpretation of the Data

In general, India has produced very little disaggregated data on disability so it is difficult to know which groups are most affected (National CRPD Coalition-India, 2019). With that said, the overall epidemiological trend appears to be higher prevalence of ID among SCs and other religious and ethnic minorities (except for STs), males, younger people, people of low socioeconomic status, people in rural areas, and lower prevalence among STs. Severities of ID will be discussed below. The excess burden of ID among SCs, other religious and ethnic minorities, people of low socioeconomic status, and people in rural areas is likely due to these groups having less access to resources and health services. As such, non-genetic causes of ID will be more common among them. The data for STs, gender, and age is more difficult to account for.

It remains unclear why the rate of ID among STs, who like SCs, people in rural areas, and people of low socioeconomic status are economically marginalized on average, is relatively low. One plausible explanation is that beneficial health practices exist in the relatively isolated cultures of ST communities, which function as preventative measures. This is at best a hypothesis to be tested, however, and at worst already contradicted by Lakhan and Sharma's (2010) fieldwork showing that most elements of the knowledge, attitudes, and practices of STs toward disability are on average worse-informed than those of non-STs in a similar geographic area. It is also possible that the census under-enumerated cases of ID among STs, though this again raises the question of why this should have been more the case among STs than, for example, SCs.

The higher rate of ID among males than females in India is generally consistent with the data from other countries. Globally, female-to-male ratios of 0.7:1-0.9:1 among adults and of 0.4:1-1:1 among children and adolescents have been reported (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2013; Ke & Liu, 2019). One cause of these imbalances is linked to genetics, as demonstrated by discoveries by geneticists of specific genetic variations associated with ID, which are (to varying degrees) skewed toward males (Polyak, Rosenfeld, & Girirajan, 2015). Similarly, Fragile X syndrome, a form of syndromic ID with an established genetic origin, occurs disproportionately among males (Ke & Liu, 2019). On the other hand, social factors may also play a mediating role. Kumari et al. (2009) hypothesize that lower reported rates of mental disability among women than men are due to higher stigma surrounding women with disabilities. This explanation is reasonable for cases of psychosocial disability, the main focus of Kumari et al.'s article, given that conditions such as anxiety disorders and major depressive disorder can be hidden with effort. ID, on the other hand, is measured by tests of ability, meaning that if a person cannot achieve a certain score on a test they have no way to hide the result. While the census data were not gathered through administering tests, the data of other studies cited have been. A plausible social explanation, however, is that data for these studies were collected based on impairments only, not social barriers. In other words, the data were collected in accordance with the medical model, which may have led to the under-enumeration of women with disabilities given that women in India face more social barriers than men. Appropriate criteria for identifying ID accurately will be discussed in the next section. The gender gap reported among PwIDs in India is therefore likely due to a combination of innate (i.e., due to genetics) and environmental (i.e., due to the system of measurement) factors.

The higher prevalence of ID in younger age groups is likely to due to high mortality among adults with ID in India and resulting low life expectancy (Lakhan & Kishore, 2016). Another possibility is that the incidence of ID is increasing over time, a hypothesis which cannot be assessed given the lack of good prevalence data for India in general. In contrast, however, the incidence of ID has been decreasing over time in the United States (Lakhan & Ekúndayò, 2017). Regardless of the cause of the higher prevalence in lower age groups, Lakhan and Ekúndayò (2017) note that life expectancy has been rising for PwIDs in other countries in the developing world and thus probably in India (though specific data for India does not exist), meaning prevalence of ID in older age groups will likely increase.

Good data on the prevalence of ID by severity in India remains elusive. The results of Sharma and Ramakrishna (2013) and Kashyap et al. (2012), the two available studies noted above, are not representative of PwIDs as a whole because they included only those who were certified and those who sought certification, respectively, possibly to the exclusion of some less severe uncertified cases. Ke and Liu's (2019) and Srour and Shevell's (2014) international estimates showed severe and profound ID as most common, while disagreeing significantly on the exact distribution. Without an analysis of the causes of ID in India compared to those in other countries, however, generalizing these results remains an uncertain method of analysis. Also worth noting is the observation of Kishore et al. (2019) that the gender gap in ID worldwide appears to disappear when considering only more severe cases. Applying this to India also remains conjectural until data comparing severity and gender for India becomes available.

Assessment of the RPwD Act's Provisions

The RPwD Act should be praised for taking an intersectional approach by including provisions specifically targeting PwDs who also face other forms of marginalization, such as giving women with benchmark disabilities priority in poverty alleviation programs. However, the Act's intersectional focus will be limited in effect because it usually just adds "especially X" to provisions that apply to all PwDs anyway, or in some cases simply adds "including X." For the law to achieve more, a key intersectional provision should have been included concerning employment reservations. As noted above, employment reservations have been described as the most important provision in the Act by Friedner et al. (2018). The suggested change will be discussed below in the section on employment.

Groups marginalized by caste and religion also needed to be mentioned more. Reserved spaces for SCs and STs on central and state advisory boards are tokenistic and inadequate to meet the needs of marginalized caste groups, because there are a large number of people on these boards and the SC representative and the ST representative will thus have little capacity to ensure benefits reach PwDs from marginalized caste groups. Furthermore, the advisory boards do not make policies themselves, but are rather “consultative and advisory bod[ies]” (Gazette, 2016). The law should also have included provisions to help PwDs from disadvantaged religious minorities including India’s Muslim community. This would be complicated politically, however, given that the general view of the ruling BJP is that elites have already given Muslims a position of undue privilege in Indian society (McDonnell & Cabrera, 2019).

The uncertainty over the prevalence of ID in India by severity may be less consequential than it first appears. While certification into different severities of ID affects the level of disability accorded to a given person, mild, moderate, severe, and profound ID all qualify a person for benchmark disability, meaning a disability certificate and the same disability benefits (Gazette, 2018). Severity would only contribute to certification for high support needs, where even the difference between mild and profound ID contributes only 10 out of the 60 necessary points (Gazette, 2019b).

Research Question #2

What is the nature of the certification process specified by the RPwD Act for PwIDs and how appropriate is it for the needs of PwIDs?

The certification process includes the definition and classification of ID, the screening mechanism, the administrative process for certification, the certification criteria for benchmark disability, and the certification criteria for high support needs. Each of these aspects in the certification process is inadequate in some regard.

The overall definition of ID in the Schedule of the RPwD Act is inadequate because it is based entirely on the medical model of disability and thus fails to consider environmental and attitudinal factors. This concern will be discussed more below in the context of criteria for the certification of benchmark disability and for high support needs. The RPwD's three levels of disability (that is, disability, benchmark disability, and benchmark disability with high support needs) are a welcome addition to the Act, on the other hand. They will allow people with disabilities who do not reach the 40% threshold for benchmark disability to benefit from general provisions on health care, education, employment, and other areas. Likewise, those for whom the benefits for people with benchmark disabilities are not adequate can be certified to receive additional support for their high support needs.

The five-year survey of children with disabilities in schools is appropriate, as is the provision in the guidelines for referrals. However, a psychometric instrument for screening should have been specified to reduce the scope for individual bias to impact the process.

The findings show division as to whether the administrative process for the certification of benchmark disability as stipulated in the 2018 guidelines for the RPwD Act was too difficult. That said, the sheer number of professionals required to approve the assessment (the medical board consists of four professionals) appears to be an obstacle for certification, particularly in rural areas where all respondents who were asked agreed there are few professionals available. The problem is especially acute because ID is an "invisible" disability and its presence is thus less straightforward to ascertain than the presence of a physical disability. The process should be streamlined as it was in the 2009 amendment to the rules for the PwD Act or in some comparable manner, especially for rural areas.

The key question for disability certification in India is which criteria should be used to allocate the certificates. Within the current medical approach, two technical modifications to the criteria deserve mention. Firstly, the use of SQ as specified in the 2018 guidelines for the RPwD Act is incorrect and should have been measured relative to age. Secondly, IQ should possibly be replaced with DQ due to its wide use in India, though determining the relative merits of these two psychometric tests is a complicated issue this thesis will not have space to address. In any case, the predominance of the medical approach in the certification process is cause for concern. The IQ and SQ tests fail to account for attitudinal barriers caused by social, cultural, and religious factors. Because of these failures, the approach tends to miss the environmental barriers that disproportionately affect people from marginalized groups. Medical criteria also rely solely on the doctor's expertise to the exclusion of the opinions of actors more acquainted with various areas of a person's life, making differentiating disabilities more difficult.

At the same time, the opposite option of using entirely social criteria also has limitations. For one thing, it deserves mention that despite their diametrically opposed opinions overall, two participants agreed that there are not currently criteria in existence that could certify ID based on the pure social model. While the Washington Group questionnaires exist for epidemiology, they may not work for certification. One key problem is that they rely entirely on self-report. Because disability certification unlocks valuable benefits for individuals that are costly for the government to provide, self-reporting could open the way for fraud. While there is no incentive to fraudulently represent oneself as having a disability for census purposes, there is a financial incentive to fraudulently represent oneself as having a disability in order to gain a disability certificate and the associated benefits.

There are, however, alternate approaches for social criteria. The most promising approach appears to be consulting a range of stakeholders, thereby allowing for cross-referencing various points of view. The results will therefore not be overly biased by any given contributor to a final judgement. From a biopsychosocial perspective, disability is not entirely a product of the environment; it stems from the interaction between individual impairments and the environment. ID cannot be understood by analysis of the people around a person unless that person's individual traits are also assessed. As such, a mixed approach would incorporate the strengths of both medical and social criteria and best identify PwIDs for certification in order to deliver disability benefits.

The findings also suggest three major problems with the criteria for high support needs. Firstly, the criteria for high support needs are specified in much less detail than the criteria for benchmark disability found in the 2018 guidelines for the RPwD Act. The critique that they are too vague appears valid. Too much room for individual discretion could introduce bias and compromise standards, leading to some caregivers not receiving an additional pension despite the considerable attention needed by the PwD for whom they are caring. Likewise, some caregivers caring for PwDs with lower needs may receive the pension and thereby take up resources they do not need from strained state disability budgets. Secondly, the critique that the criteria are insensitive to socioeconomic status is also valid. For example, one criterion assesses toilet hygiene (Gazette, 2019b). In reality, many people in India continue to lack adequate access to toilets despite recent progress due to a major government initiative (Kuchay, 2019). Finally, the criteria for high support needs are inadequate because they are based on the medical model of disability to too great an extent. While two social criteria have been included and this is a positive development, they account for only 10 of 100 possible points. As with the certification for benchmark disability, criteria should have included consultation with other people who could help illuminate the specific needs of a given PwD.

Research Question #3

What kinds of needs of PwIDs must be met in order for them to have dignity and equality, and to what extent are these needs adequately addressed by the RPwD Act?

The findings of this study reveal six key topics related to dignity and equality: discrimination, awareness campaigns, institutions, privacy, research on PwDs, and disability-selective abortion. The RPwD Act includes clear provisions to prevent research on PwDs without their consent and the permission of an appropriate committee, which if implemented as written will adequately protect PwIDs from being researched upon in a way that violates their dignity. On all five other topics, however, the Act fails to adequately safeguard the equality and dignity of PwIDs.

With respect to non-discrimination, the RPwD Act fails to protect PwDs from discrimination by including exceptions in the provisions that are nominally intended to guarantee non-discrimination and reasonable accommodation. This is consistent with Friedner et al.'s (2018) description of the Act's non-discrimination provisions as "vague." The definition of reasonable accommodation should have been more specific to ensure that it could not be used as a pretense for unfair discrimination. The provision in section 3, subsection 3 that allows for exceptions to the general non-discrimination rule could then have been entirely removed, given that any case that imposed undue hardship would already be exempted under the reasonable accommodation provision.

The RPwD Act's overall stance on raising awareness about disability is appropriate. It is somewhat undercut, unfortunately, by the fact that the Act itself uses medical definitions of disabilities, including ID, which in turn implicitly validate the charity model of disability. It is unlikely the government will promote awareness about ideas it does not include in its own legislation.

It must also be borne in mind that the government does not possess infinite resources with which to reshape the cultural attitudes of the country's population. The government must therefore focus its awareness efforts where they will make the most difference in the lives of PwDs: in schools, workplaces, and health centres, and among PwDs and their caregivers and families. The RPwD Act's provisions to reduce negative social attitudes toward PwDs among employers and educators are adequate from a legislative perspective. However, the absence of measures geared toward increasing awareness specifically among health care providers is of great concern. This is despite the fact that most doctors in India know very little about disability or certification (Mishra et al., 2012). Regarding caregivers and families, the Act does contain the goal (mentioned above) of "respect for the decisions made by persons with disabilities on all matters related to family life, relationships, [and] bearing and raising children" (Gazette, 2016). Unfortunately, it does not specify the target group among whom this respect should be fostered. If families are the target it effectively meets the need to sensitize them, but if they are not there is an important gap. Sensitizing families is doubly important because helping them understand the needs of their child(ren) with ID will in turn lead to greater awareness among PwIDs themselves. Although awareness among the population at large is not as high a priority as families and service providers, the Act should also have been clearer that this was an eventual goal.

Based on the results, institutions are one of the greatest factors harming PwIDs in India today despite holding only a small percentage of PwIDs. As noted in the literature review, women and girls in particular suffer inhumane conditions. There are some PwIDs who have nowhere else to live and so it is necessary that the government provide them with accommodations, but these should not be closed or involuntary. The RPwD Act or its 2017 rules should have mandated community-based institutions so that PwIDs could explore their locality and enjoy social interactions with people without ID. At a minimum, the Act should have included regular inspections for institutions, significant penalties for institutions that fail to live up to them, and penalties for states that fail to conduct effective inspections. The RPwD Act's guarantee of support arrangements for PwDs to exercise legal capacity does mitigate the problem of involuntary confinement but will be of no use to PwIDs whose legal capacity has been removed by legal guardianship, as is also provided for under the RPwD Act. This problem will be discussed in more depth in the next section.

A concern about privacy also emerged from the findings. The range of identifying information such as address seen on the disability certificate for ID (Form VII of the rules for the RPwD Act) may equally be needed for people without disabilities to access other types of benefits. However, the type and severity of disability is clearly stated on the certificate and yet is not necessary to identify the person; the government should instead provide a separate document for accessing benefits that only includes necessary identifying information. This would suffice for most situations, such as collecting railway concessions or the monthly pension, whereas the full disability certificate could be used for situations such as applying for reserved government positions. Privacy concerning the type and extent of disability is especially significant for ID, which is not outwardly visible.

On the question of disability-selective abortion, there is a tension between women's freedom as individuals to choose and the freedom of PwDs as a group from discrimination on the question of disability-selective abortion. The question continues to be discussed in the world's scholarly literature (see for example Heyer, 2018; Gould, 2019). Abortions of fetuses with Down syndrome, a form of syndromic ID, have been a focal point for controversy (Heyer, 2018). Unfortunately, space does not permit a fuller exploration of this important debate, so I will rely on the collective view of India's DRM (reported by a participant in the "Results" section), which is opposition to disability-selective abortion. India's Medical Termination of Pregnancy Act, 1971 allows abortion based on severe disability, however, and an amended version may soon be passed extending the duration during which abortions can be accessed on such grounds (Sharma, 2019b; 2019a). The RPwD Act remains silent on the matter and thus fails to protect PwIDs from disability-selective abortion.

Research Question #4

What is the nature of the needs of PwIDs with regards to legal guardianship, and to what extent are these needs adequately addressed by the RPwD Act?

Before considering whether the guardianship provisions of the RPwD Act should have been included, it is important to recognize some common ground occupied by both sides of the debate. The provisions of the RPwD Act do say that decisions by the guardian are to be made "in consultation with [the PwD]," that the PwD has the right to dispense with the guardian if they so choose, and that the guardianship is limited rather than plenary (Gazette, 2016). Opponents of the guardianship advocate assisted decision-making, instead of leaving PwIDs alone without support to navigate complexities they struggle to understand. The difference of opinion, arguably, is over who should be trusted to make the final decision if the opinions of the caregiver and the person with ID do not converge after consultation.

Both advocates and critics of legal guardianship point to potential risks to the interests of PwIDs if their position is not adopted. Advocates and critics also concede there are risks associated with their own position, but consider them less significant than the risks associated with the other position. Ultimately, it is an empirical question whether it is more likely that the legal guardian of a person with ID who inherits property will invoke the guardianship to seize the property, or whether it is more likely that somebody else would manipulate a person with ID's difficulty making complicated judgements to gain their property in the absence of a guardian. These two eventualities are not equally undesirable, however. Not only has one participant said the former is two to three times more common in her experience, but the outcome of the former is much worse for the person with ID. In either situation, the person with ID would lose their property, but at the hands of a legal guardian they could be sent to an institution with dire living standards, whereas otherwise they would still be left with their caregiver. The wellbeing and basic needs of PwIDs must take precedence over other factors.

It is therefore my view that the guardianship clause is an unwelcome provision in the RPwD Act, and indeed a holdover of colonial-era British policy. In its place, provisions for assisted decision-making would have better respected the rights of PwIDs. Such provisions would admittedly not be a panacea. Two participants observed that assisted decision-making for PwIDs is a cultural as well as legal phenomenon and that India was at best beginning a transition toward a mindset in which assisted decision-making would be possible. Nevertheless, even in cases where PwIDs' capacity to make independent decisions was not fostered, in the end their guardians would make the decisions, so it would be no worse than under the legal guardianship regime. Thus, it is best that the legislative aspects of the "right to decide" for PwIDs be put in place, as a first step toward broader social change.

Research Question #5

What is the nature of the health, education, and employment needs of PwIDs and to what extent are these needs adequately addressed by the RPwD Act?

The four themes that emerged under this research question were the RPwD Act's provisions on health, education, employment, and reproductive health and education. The RPwD Act appears to have incorporated adequate provisions to improve the health of PwDs. The three major health areas of health care, rehabilitation, and prevention of disability have been addressed by the RPwD Act. That said, as noted in the literature review, PwIDs in developed countries often suffer negative health outcomes as the result of sedentary lifestyle and substance abuse, and this may increasingly be the case in India as life expectancy of PwIDs increases. My only criticism of the RPwD Act with regards to health is a lack of proactive measures to improve health-linked behaviors among PwIDs and thereby prevent greater health care costs in the future.

Regarding education, the RPwD Act includes a range of provisions for the education of PwDs, most of which are commendable. The point of disagreement has been the value of inclusive education as compared to special education. While literature from India has suggested children with severe and profound ID would benefit more from special education, the international literature shows that inclusive education generally produces greater benefits for children with all severities of ID.

The question then arises which of set of literature is applicable to the current situation in light of the participant comments described above. The concerns that the necessary resources and infrastructure are not in place for inclusive education are one reason for doubting inclusive education will be more beneficial. Another issue is the extensive pedagogical changes described that are needed to make inclusive education a reality. With these concerns in mind, it is understandable that some parents might currently prefer to place their children with ID in special schools designed specifically for the purpose. At the same time, because special schools are often not available in rural and impoverished areas, some parents will prefer inclusive education for their children with ID. Given these circumstances, the RPwD Act's provision granting children with benchmark disabilities the right to go to an inclusive or special school of their choice is reasonable and will be conducive to the best possible educational outcomes for PwIDs. It also facilitates greater autonomy for PwIDs in choosing the school and peer group in which they would rather learn. At the same time the RPwD Act explicitly includes the goal of full inclusion, which the country can work toward as educational infrastructure improves.

Turning to the labour market, the RPwD Act's provisions on employment are generally strong. The requirement for awareness campaigns to target employers and coworkers will be helpful if implemented. It is also my view that the provision for employment reservations, while imperfect, will advance the interests of PwIDs. While a quota system is less desirable than a situation in which PwDs are simply hired due to awareness about the strengths they possess despite their disabilities, it is an improvement over the status quo that preceded it. The provision limiting each category of PwDs to certain types of jobs should not have been included, however. Instead, while any particular person with ID may well not be qualified for many jobs, applicants should be judged as individuals based on their personal strengths and weaknesses.

The other issue I believe exists with the employment reservations for PwDs in the RPwD Act is that they are not based on an intersectional approach. That is to say, within the 1% quota, there are no provisions guaranteeing a certain number of spots to SCs, STs, or other groups. India has for a long time guaranteed a portion of government positions to members of disadvantaged caste groups, but it is unlikely these will go to PwDs, and even less likely that they will go to PwIDs. Likewise, marginalized groups such as SCs and STs will probably receive a disproportionately small number of positions within the reservations for PwDs. Effectively, this results in the people who live at the intersection of multiple forms of marginalization benefiting the least from the RPwD Act's provision intended to help the marginalized. It would have been better if SCs, STs, women, and perhaps other groups had received a reserved proportion of the 1% of government jobs reserved for people with mental and multiple disabilities. Ideally, SCs and STs would have received the same reserved fractions (15% and 7.5% respectively) as they do in government positions where disability is not a factor (Louis, 2003).

The requirement for state governments to provide financial incentives to private enterprises to have 5% of their employees be PwDs could potentially have been a noteworthy provision, much like the government employment reservations. The inclusion of the phrase "within the limit of their economic capacity and development" has left the provision ineffectual, however. That phrase should not have been included, and that provision should have been made economically realistic through other means. Two possibilities include lowering the quota from five percent and transferring the financial burden to private enterprise by enforcing the requirement through penalties rather than financial incentives.

With respect to reproductive health and education, under the RPwD Act women cannot be forced to undergo sterilizations, meaning that in this case the Act has protected the reproductive rights of PwIDs. However, the reproductive rights of women with ID can be overridden by a caregiver empowered with legal guardianship (already discussed above) or with the clause allowing for women with severe disabilities to be forced to have abortions against their will.

Reproductive education for adolescents is especially important in India because of rising levels of HIV/AIDS infection, sexually transmitted diseases, and teenage pregnancies (Tripathi & Sekher, 2013). Inclusion of sexual education in the curriculum for adolescents with ID would only be possible if it were included in the general curriculum, however. As is, the RPwD Act offers only a vague promise of accessible information on reproductive and family planning that is not further spelled out in the rules for the RPwD Act. The societal context for inclusion of such information in the curriculum is that classes on sexual education for adolescents in general are highly controversial in India (Ismail, Shajahan, Rao, & Wylie, 2015). Indeed, a committee formed by the Rajya Sabha, the upper house of India's parliament, found that sexual education for adolescents would contravene Indian morality (Tripathi & Sekher, 2013). With this in mind, the RPwD Act's omission in regard to sexual education for PwDs in schools is unfortunate but not unexpected.

General Reflections

Probably the key question for the RPwD Act, where its provisions are attuned to the needs of PwIDs in India, is whether they are implemented despite the rule of law in that country being flawed in a range of ways. Nonetheless, at the very least those provisions in the Act provide a reference point for the activism of the DRM in India. As the first research to comprehensively explore the effects of the RPwD Act on PwIDs, this study can serve as a reference point for future scholarly work, which can help inform efforts toward meeting the needs of PwIDs in India. Understanding the Indian case will also be valuable for comparative work on the needs of PwIDs in other developing countries, given India's important status as the second-most populous developing country.

Limitations of the Study Design

The length of the interviews and number of interview participants were not sufficiently large to allow for asking every question to several participants. This means that some of the opinions gathered in responses to questions that were asked only once or twice may be outliers. Nevertheless, because opinions were not taken at face value but were instead assessed based on the strength of the arguments and evidence presented in their favor, it is my belief that the negative effects of this methodological limitation on the quality of the research have been significantly mitigated.

The sample of respondents was not necessarily representative of experts on ID in India or experts on disability more generally in India. Potential participants to be contacted were chosen based on the criteria described in the study's "Methodology" section, but because the response rate was under one third and the sample was small (n = 9) they may disproportionately represent certain viewpoints. This limitation was mitigated by consultation of academic and grey literature and again by the fact that the viewpoints were not adjudicated by majority opinion but by the merits of their supporting arguments.

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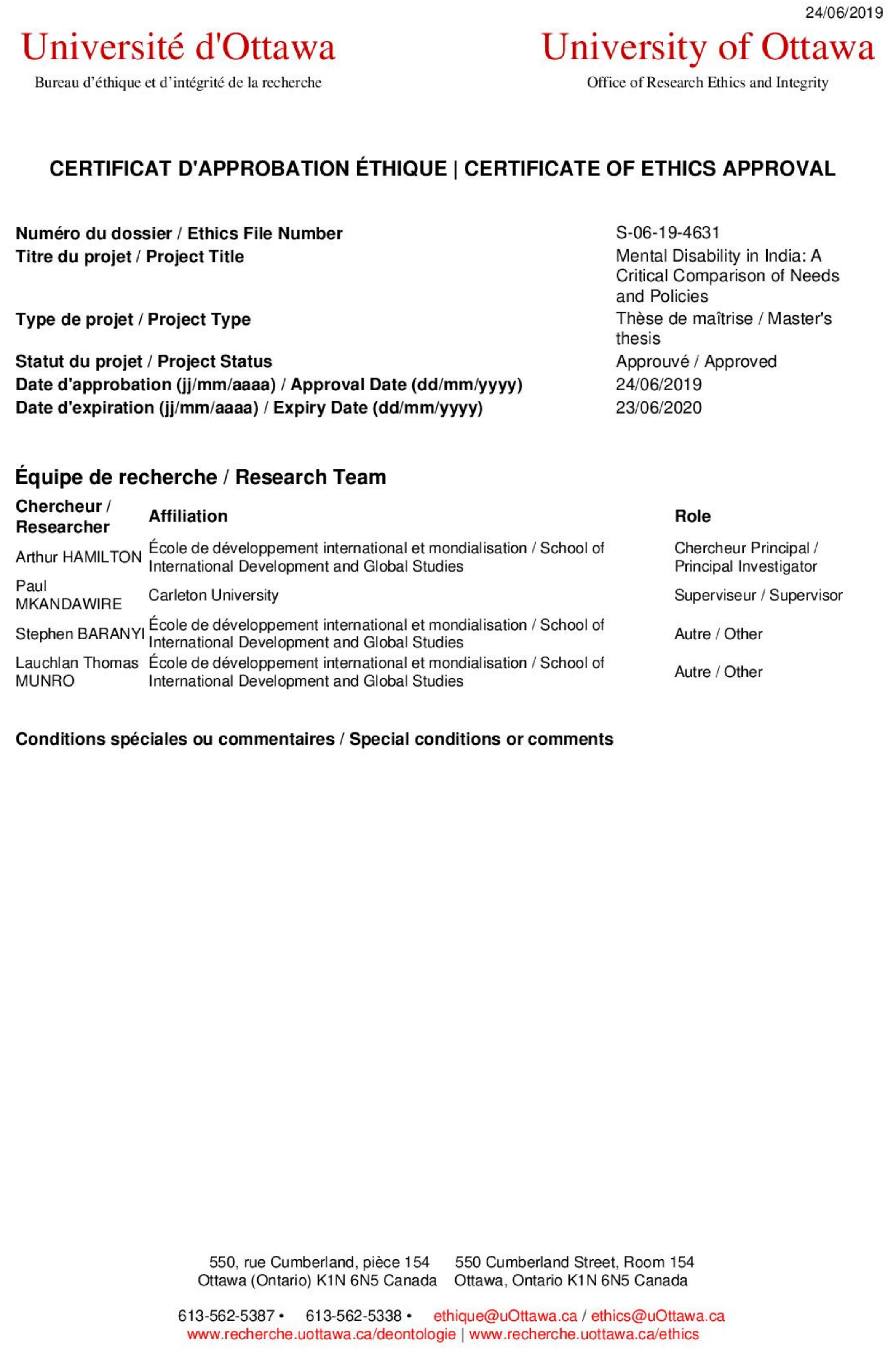
Appendix A

Final Research Ethics Board Approval

On 24 June 2019 I was granted approval to conduct research on human subjects by the University of Ottawa's REB. The Ethics File Number is S-06-19-4631 and the approval expires on 23 June 2020. The approval certificate is included on the pages below.



24/06/2019

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	S-06-19-4631
Titre du projet / Project Title	Mental Disability in India: A Critical Comparison of Needs and Policies
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	24/06/2019
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	23/06/2020

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
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24/06/2019

Université d'Ottawa
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University of Ottawa
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Le Comité d'éthique de la recherche (CÉR) de l'Université d'Ottawa, opérant conformément à l'*Énoncé de politique des Trois conseils* (2014) et toutes autres lois et tous règlements applicables, a examiné et approuvé la demande d'éthique du projet de recherche ci-nommé.

L'approbation est valide pour la durée indiquée plus haut et est sujette aux conditions énumérées dans la section intitulée "Conditions Spéciales ou Commentaires". Le formulaire « Renouvellement ou Fermeture de Projet » doit être complété quatre semaines avant la date d'échéance indiquée ci-haut afin de demander un renouvellement de cette approbation éthique ou afin de fermer le dossier.

Toutes modifications apportées au projet doivent être approuvées par le CÉR avant leur mise en place, sauf si le participant doit être retiré en raison d'un danger immédiat ou s'il s'agit d'un changement ayant trait à des éléments administratifs ou logistiques du projet. Les chercheurs doivent aviser le CÉR dans les plus brefs délais de tout changement pouvant augmenter le niveau de risque aux participants ou pouvant affecter considérablement le déroulement du projet, rapporter tout évènement imprévu ou indésirable et soumettre toute nouvelle information pouvant nuire à la conduite du projet ou à la sécurité des participants.

The University of Ottawa Research Ethics Board, which operates in accordance with the *Tri-Council Policy Statement* (2014) and other applicable laws and regulations, has examined and approved the ethics application for the above-named research project.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completedfour weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

Riana MARCOTTE
Responsable d'éthique en recherche / Protocol Officer
Pour/For **Barbara GRAVES** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences sociales et humanités / Social Sciences and Humanities Research Ethics Board**

Appendix B

Caste in India

The Indian caste system was classically described as static and based upon Hindu strictures by Louis Dumont in 1970, but further research and debate has shown it is in fact a complex and dynamic social hierarchy influenced by political, economic, religious, and cultural factors (H. Singh, 2008). Caste was discussed with great interest by the British, but it appears that their conceptualization does not correspond neatly to either the four idealized *varnas* ("colors") of society described by (some) Hindu texts or the thousands of *jatis* ("births") actually observed in Indian society (Samarendra, 2011). It should also be noted that while the theoretical concept of *varna* is of Hindu provenance, the practical concept of *jati* encompasses people of all religions in India (Singh, 2018).

Presently, the government of India divides *jatis* into three categories: Scheduled Castes (SCs), Other Backward Castes (OBCs), and Forward Castes (Desai & Dubey, 2012). Members of SCs have been referred to as *untouchables* (by the British) and *harijans* (by Mohandas Gandhi) (Charsley, 1996). More recently, it has become polite to refer to members of SCs as *dalits* (Charsley, 1996). SCs were the lowest members of the system, occupying a place below the four formal *varnas* in theory and generally also the least desirable occupations, such as that of street sweeper, in practice (Charsley, 1996). They were and still often are, despite legislation forbidding the practice, subject to untouchability (Maity, 2017). SCs account for 16% of the population of India (Jensenius, 2015). Other Backward Classes (OBCs), who represent about half of the Indian population, are groups who were historically disadvantaged castes but, unlike

SCs, not beneath the caste system (Jaffrelot, 2000). Both SCs and OBCs are the beneficiaries of affirmative action hiring practices under the Indian constitution (Aygün & Turhan, 2017).

STs are groups who were not historically part of mainstream Indian society, frequently living in more remote areas of the country (Maity, 2017). STs have often been referred to as indigenous people of India, though this designation is controversial among anthropologists; *adivasis* ("original inhabitants") is a preferred term (Maity, 2017). STs were identified by the British as practicing animism. More recently, though, many have changed their identification to Hinduism or Christianity (Maity, 2017). As a result it is more useful to consider STs as an ethnic group than a religious one. STs constitute 8.6% of the national population according to the 2011 census (Jayakumar & Palaniyammal, 2016). Like SCs and OBCs, they are eligible for affirmative action provisions under the Indian constitution (Aygün & Turhan, 2017).

Appendix C

Sample Recruitment Email

The emails used for researchers, DPO representatives, and officials were differentiated in small ways but followed broadly the same format. The emails were also modified in the cases in which I had prior contact with the recipient or in which I had a mutual connection with the recipient. The email that follows was sent to a researcher with whom I had no prior contact. (The text seen below is reformatted according to the style used in this thesis.)

Dear Dr. [redacted],

I hope you are doing well. My name is Arthur Hamilton and I am a researcher at the University of Ottawa in Canada. My Master's thesis is examining the extent to which India's Rights of Persons with Disabilities Act, passed in 2016, meets the needs of people with intellectual disability (ID). One element of my methodology is conducting interviews over Skype with people doing related work, including representatives of Organizations of Persons with Disabilities (DPOs), researchers, and government officials.

During my literature review of ID in India I found your work very valuable and I believe you could contribute meaningfully. Participating would mean doing a single interview for about one hour (or less, as needed) at a date and time that are convenient for you (in your time zone) within the next month. While the audio of the interview would be recorded, you would remain anonymous in the research unless you chose to have your affiliation and/or name included. You would also have the option to withdraw at any point during the process.

Please let me know of any questions you may have at [redacted] and I would be happy to answer them. If you are willing to participate, I can send you further details and a consent form. I would be very grateful for your participation.

Thank you very much for your time and I look forward to hearing from you.

Kind regards,

Arthur

Appendix D

Interview Consent Form

The consent form below was sent to all participants. As was approved by the REB, the participants were given the option to fill out, scan, and email the form or to give verbal consent to the contents of the form at the start of the interview. The form sent to participants was additionally placed on the letterhead of the University of Ottawa's School of International Development and Global Studies (SIDGS). (The text seen below is reformatted according to the style used in this thesis.)

The purpose of the research project is to study the ways in which India's Rights of Persons with Disabilities Act, 2016 meets or does not meet the needs of people with intellectual disability. The research will be conducted by Arthur Hamilton, who is completing his Master's degree at the University of Ottawa's School of International Development and Global Studies and whose email address is [redacted]. It is supervised by Prof. Paul Mkandawire, who is co-director of Carleton University's Institute of Interdisciplinary Studies and whose email address is [redacted]. The participant may contact the researcher or his supervisor with any questions about the study.

The research was reviewed by the University of Ottawa's Office of Research Ethics and Integrity. If the participant has any questions regarding the ethical conduct of this study, they may contact the Protocol Officer for Ethics in Research (at the University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5) by phone at +1 613-562-5387 or by email at ethics@uottawa.ca.

By agreeing to participate, the participant agrees to be interviewed remotely via Skype for about one hour (or less, as needed). They will have the choice of whether the audio may be recorded, which they can indicate below. In addition, the participant will remain anonymous by default and will be identified by a number and whether they are an Organization for People with Disabilities (DPO) representative, a researcher, or an official (that is, they might be referred to, for instance, as “DPO representative 3”). They will be referred to with gender-neutral language and their identity will not be shared except with the three members of the thesis’ supervising committee. If the participant wishes, they can indicate below that their affiliation and/or name may be included in the research, but this is not necessary for the research.

The recording and transcript from the interview will be kept on the researcher’s personal computer, USB drive, and cloud storage for at least five years after the research is completed but will not be stored anywhere else. All of these are password-protected. In order to minimize the risk of security breaches and to help ensure the participant’s confidentiality it is recommended that they use standard safety measures such as using a secure connection for the interview and signing out of their account, closing their browser and locking their screen or device afterwards. The research is fully funded by the researcher, and as such no monetary compensation can be offered for participating. The research will be potentially valuable to DPOs, policymakers, and other researchers, all of whom directly or indirectly have the opportunity to improve the lives of people with disabilities in India.

The risk from participating is minimal. Nevertheless, to reduce the risk that the participant will be negatively emotionally impacted due to participating, the interview questions have been reviewed by the Research Ethics Board and will not cover the personal experiences of the participant. If for any reason and at any time the participant no longer wishes to be a part of the study, they are free to withdraw. Their contributions will then be removed from the research and data from their interview will be completely destroyed.

By signing below I indicate that I have read and understand the above, that I agree to participate in an interview for the study, and that I have selected ONE of the first three boxes below AND also ONE of the last two boxes.

☐ I prefer to remain fully anonymous in the research.
☐ I give permission for my affiliation to be included in the research, but not my name.
☐ I give permission for my name and my affiliation to be included in the research.

☐ I prefer for the audio of my interview not to be recorded.
☐ I give permission for the audio of my interview to be recorded.

Participant’s signature: ______________________________ Date: _______________________
Researcher’s signature: ______________________________ Date: _______________________