Women’s Experiences of Disability and Community-based Rehabilitation in Sri Lanka

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The majority of people with disability (PWD) live in the global South. Over the last four decades, community-based rehabilitation (CBR) programs have come to dominate the way development programs operate and intercede in the lives of PWD, especially in low- and middle-income countries. This research uses participant observation at five CBR programs and 52 in-depth interviews, across thirteen months of fieldwork, in order to gather women’s experiences of disablement and CBR in Sri Lanka. Findings detail ways CBR programs fail to address larger social inequities, specifically centered around ableism and sexism, and how these barriers are embedded in society. Programs often target rehabilitation efforts at the individual level without changing shared social circumstances of discrimination. CBR programs are intended to be more empowering than segregated forms of rehabilitation, yet few CBR-related studies use methods to incorporate the perspectives of PWD. Centering the experiences of women with disability (WWD) in CBR programs in Sri Lanka, this dissertation reveals glaring deficits in the CBR framework and argues perspectives of WWD are valid and important sources of knowledge needed to inform research and practice. Three main themes connect: inadequate childhood education and current employment experiences; a myriad of social factors shaping health and well-being; and an increase in mobility through social movements. Findings illuminate the need to refocus international development and intervention efforts away from individual deficit-based models in favor of systematic societal-level interventions informed and guided by the experiences of people the programs aim to serve.
Women’s Experiences of Disability and Community-based Rehabilitation in Sri Lanka

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B.A., Auburn University, 2007
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WOMEN’S EXPERIENCES OF DISABILITY AND CBR

APPROVAL PAGE

Doctor of Philosophy Dissertation

Women’s Experiences of Disability and Community-based Rehabilitation in Sri Lanka

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CHAPTER 1. INTRODUCTION: WOMEN’S EXPERIENCES OF DISABILITY AND COMMUNITY-BASED REHABILITATION (CBR) IN SRI LANKA

No doubt, the activities of the nation state are themselves related in complex ways to regional and global geopolitical trends, but it is the local face of this international phenomenon against which one is moved to struggle. (Mani, 1990, p. 29)

I identified a community-based rehabilitation (CBR) program that agreed to host my research on a dry and cloudy day, seven months into fieldwork. It was happenstance. I walked by the organization going to a friend’s house. I was living in a different part of the country when a friend asked if I would accompany her to a wedding party. She was born and raised in America and her parents are Sri Lankan. Both of us were taller than many Sri Lankan women, and she also stood out from a crowd because her hair was cut very short. Maybe she asked me to be her plus one because she knew my research had not gotten off the ground, or maybe it was so she would not have to attend alone. Having minimal commitments and wanting to explore more of the country, I agreed to travel the long distance to attend the party with her. Friends from our grant cohort lived there and hosted us for the week.

A few days into the trip, I was walking from town center to my friend’s house on the periphery and noticed a rehabilitation center. A large sign in front of the building in English and Tamil notified me it was a center for rehabilitation. The first time I walked by the organization their gate was closed. A couple of days later, I made an effort to walk by during operating hours. I walked inside, through an open tall metal gate. There was an older man seated behind a desk on the porch with a large, seemingly well used, ledger in front of him. I arrived alone, without an interpreter, and inquired about speaking with the director to learn more about the organization. The man walked a few feet inside the entryway to a small room with four desks, two with large desktop computers. Three of the four desks were empty. One was occupied by a man who later
became my main contact within the organization. The security guard/receptionist grabbed a chair and waived for me to sit down in front of the man. He stood up and shook my hand with a welcoming smile. I explained why I was in Sri Lanka, my intent to learn more about community-based services and experiences of women with disabilities, and showed him the recruitment forms. Much to my surprise, after seven months of trying to identify CBR sites to work with, he invited me to begin the following day. I was grateful to have someone so readily accept. I submitted documents for ethics approvals from the University of Connecticut and the University of Colombo to do research in an additional language, and two weeks later, at the end of May 2017, I began CBR program observations at the first of five sites. Appendix A lists common acronyms and abbreviations used throughout the dissertation. All field sites and all informants are referenced using pseudonyms.

**Centering the Global South/South Asia**

This dissertation prioritizes adult women’s experiences of social disablement in Sri Lanka. The United Nations (UN) reports people with disability (PWD) are the world’s largest minority population (UN, 2020). The World Health Organization (WHO) reports 15% of the world population are individuals living with disabilities, with estimates higher in lower income countries (WHO, 2018). Despite a high prevalence of disability, low- to middle-income countries are vastly underrepresented in evidenced-based research (Bornstein et al., 2012). For example, Bornstein and colleagues report over 90% of developmental science literature comes from communities that account for only 10% of the world population. This representative gap in literature is even more pressing considering an estimated 80% of PWD live in countries with minimal economic resources (WHO, 2018).
The current research sometimes uses “global South,” a term interchangeable with “Third World,” “developing countries,” and “lower- and upper-middle-income-countries” (LMICs/UMICs). The use of global South is not a geographic demarcation, but signifies regions with high levels of both individual and national poverty, histories of colonization, imperialist governments, and economies primarily based on exporting raw materials (Funk, 2015). An estimated one billion individuals world-wide live with some form of disability (UN, 2020), yet first-hand experiences of PWD remain difficult to find in “global North” research (Farrell & Krahn, 2014), and even more absent are experiences of people living in extreme poverty (Grech, 2016). Western, or global North, dominance has prolifically shaped how researchers view disability and the field of disability studies is no exception (Grech, 2011). Asia is home to over half of the world population, yet people living there are vastly underrepresented in research. For example, Arnett (2008) found only 3% of psychological research samples were located in Asia.

Disability-related research has too often omitted discussing ways colonial and Western models of development overshadow macro- and micro-examinations of local contexts, cultures, and histories. A dire need exists to widen the geopolitical scope of disability studies through the promotion of an interdisciplinary conversation related to experiences of disability in the global South (Grech & Soldatic, 2016). People living with disability may occupy multiple axes of marginalization related to gender, geography, and socioeconomic status. A western-system introduced during British colonization shapes present-day services across multiple sectors such as healthcare, education, and welfare (Fernando et al., 2003). The experiences of individuals navigating life at the intersection of interlocking oppressions in Sri Lanka often go undocumented with a few notable exceptions (e.g., Kandasamy et al., 2017a; Ruwanpura & Humphries, 2008; Samararatne & Soldatic, 2015). This dissertation aims to raise questions and
highlight glaring gaps by applying a critical lens to the experiences of women with disability (WWD) in Sri Lanka. This analytical approach stems from earlier scholarship in disability studies, discussed later in this chapter, and highlights social aspects of disability.

**Disability and Rehabilitation Frameworks**

I feel like disability is an emotion, it’s all in our mind, like we imagine it. It’s all an illusion. I am not really disabled. I feel that way after being here.* (Hiruni)

The WHO World Report on Disability (2011) defines rehabilitation as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (p. 96). The report noted the process of rehabilitation includes making changes to a person’s environment, yet exclusively focused on individual rehabilitation goals in contrast to community-level initiatives. Globally, individual rehabilitative interventions have long been prioritized over those focused on societal-level change. This dissertation uses CBR programs as starting points in order to focus on women’s experiences of disability in Sri Lanka and explore ways disability and gender are socially constructed. The current research argues disability is primarily social; therefore, a focus on community-based disablement is required to most effectively implement societal improvements. A social framework of disability is applied to this research in order to promote this paradigm shift (Oliver, 1996).

**Theoretical Framework**

Core tenets of disability studies inform our understanding of how to move forward with disability-related research and sustainable community development. According to Kanter (2010), disability studies has five core characteristics. Disability studies: is multidisciplinary; rejects disability as exclusively a personal problem; views PWD as integral parts of society; focuses on environmental and social barriers preventing inclusion; and finally, important to the aims of this
dissertation, disability studies utilizes the valuable perspective and knowledge of PWD as the foundation for research (pp. 408-409). Similar to feminism’s understanding of gender, feminist disability studies (FDS) positions disability as “a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate. … it exposes disability as a social category of analysis” (Garland-Thomson, 2005, p. 1557).

Informed by intersectionality (Crenshaw, 1991), FDS attends to ways social locations of gender, ethnicity, and class intersect with disability. The theoretical approach of this research challenges assumptions of a singular unified experience of one particular identity (such as being a woman or being Sri Lankan) and instead privileges interindividual and within-group diversity. Through this research, I aim to acknowledge the fluid nature of how, when, and where social categories are assigned and experienced by individuals and groups over time (Few-Demo, 2014; Frederick & Shifer, 2019). This work calls on a feminist critique of power related to knowledge production and argues perspectives of subordinated communities (i.e., women and PWD) are valuable and markedly different from those who traditionally reproduce knowledge (Naples & Gurr, 2014).

This research strives to broaden the scope of FDS in considering Nirmala Erevelles’ “transnational feminist disability studies perspective” (Erevelles, 2011, p. 123). This scope requires engaging in an analysis of “political/materialist” constructs and foregrounding the “materiality of structural constraints” (p. 129). Here, materiality is “the actual historical, social, and economic conditions that impact (disabled) people’s lives, and that are further mediated by the politics of race, ethnicity, gender, sexuality, and nation” (Erevelles, 2011, p. 129). Scholars argue disability continues to be relegated to the periphery of development theory and practice. This results in programs that reflect the agendas of others with very little voice given to those
impacted by development programs (Chataika & McKenzie, 2016; Chaudhry, 2019; Grech, 2016; Kuipers & Sabuni, 2016). Research ultimately fails to produce a valuable contribution when groups of people are excluded from forming knowledge that impacts them (Campbell & Gregor, 2004). This dissertation uses a qualitative paradigm to address the alienation of WWD within CBR research. In doing so, I challenge the exclusionary “social relations of research production” evident in development and rehabilitation scholarship that ignore struggles against systematic oppression and fail to combat ableism (Oliver, 1992, p. 102).

Social Model of Disability

Much of the literature on disability in the global South promotes a definition of disability put forth by the United Nation’s 2006 Convention on the Rights of Persons with Disabilities (CRPD). Sri Lanka ratified the CRPD in early 2016 (Ministry of Foreign Relations, 2017), although as detailed later in this chapter the official definition of disability was last revised in 1996. The CRPD defines a person with a disability as someone with “long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN, 2006, Article 1).

The CRPD definition contains elements of the medical model of disability, i.e., disability is a result of personal tragedy solely rooted within a person, and interventions should be tailored as such (Graziano, 2002). The CRPD also incorporates aspects of a social model where disability is not exclusively located within an individual and is a public phenomenon created by social and environmental barriers that society must work to address (Oliver, 1996; Samaha, 2007; Shakespeare, 2012). A narrow theorizing neglects social causes of disablement and privileges rehabilitation efforts exclusively located within individual bodies. These antiquated and deficit-based individual notions of disability now exist in stark contrast to modern concepts of disability.
(e.g., Hall, 2011; Kafer, 2013; Oliver, 1990; Shakespeare, 2006; Silvers, 1998; Silverstein, 2000). The CRPD definition, though a flawed global approach, may be used to shift international disability discourse toward a more critical understanding of shared external barriers that hinder equal participation. These tensions occasion considerable ethical, moral, and political debate about how to measure, define, conceptualize, and intervene upon disability (Bickenbach, 2012; Blanck et al., 2006; Hall, 2011; Kanter, 2010; Samaha, 2007; Shakespeare, 2012; Siebers, 2013).

This research includes personal symptoms of disablement on the body as well as ways bodies are experienced socially. Vandana Chaudhry’s (2019) ethnographic examination of disability development projects in India informed the theoretical framing of this work by showing ways “neoliberalism is transforming both social work and disability interventions, shaping them into individualized and depoliticized frameworks that undermine issues of social and structural inequalities in the Global South” (p. 1127). Chaudhry’s work critiques the responsibilization and individualization of empowerment frameworks that have neglected to address social aspects of disablement.

Michael Oliver’s (1990) social model is relevant in the context of this research, but has been critiqued as exclusive and lacking room for an embodied ontology (Shakespeare & Watson, 2001). Nonetheless, Oliver (1996, p. 43) notes the social model guides our understanding of:

which aspects of disabled people’s lives need medical or therapeutic interventions, which aspects require policy developments and which require political action. Failure to distinguish between these up to now has resulted in the medicalisation of disability and the colonisation of disabled peoples lives by a vast army of professionals when perhaps, political action (i.e. civil rights legislation) would be a more appropriate response.

More recently, Erevelles (2011) integrated FDS and Third World feminism to form a transnational feminist perspective of disability and increase the profile of studying disablement in a global context. This fusion provided an analytical framework to critique the imperialism and
structural violence often ignored in disability research. In adopting a decolonial framework, I do not focus on local cultures as a burden. Instead, I aim to use historical contexts to widen the lens of analysis, examining both the local and the global. This allows for a critique of contemporary empires and broad cultural practices that maintain existing power relations as well as the social oppression of large groups of people (Mohanty, 2003; Senier & Miranda-Galarza, 2016).

**Limitations of Rehabilitation**

There is value in drafting, conceptualizing, and debating complex social theories of disability; however, the aim of this dissertation is to examine existing models of disability and rehabilitation in practice. To achieve this, five CBR programs were used as sites of observation, recruitment, and critique. Rehabilitation is a socially and politically designated intervention and addressing the prevailing notion that disability is a personal tragedy is a major challenge (Samaha, 2007). Combatting stigma is also difficult for service providers (Bualar & Ahmad, 2009; Fernando et al., 2010). “Societal attitudes are significant since they determine to a large degree the extent to which the personal, social, educational and psychological needs of persons with disabilities will be realized” (Munyi, 2012, para. 32). Individual interventions are important for rehabilitative growth and development yet do not have enough impact to challenge community actions and beliefs (Munyi, 2012; Walker et al., 2011). It is necessary we adopt a socially rooted view of disability and disablement in order to inform corresponding rehabilitation efforts. Researchers studying the inclusion of PWD across the world must acknowledge culturally specific attitudes within particular religious, political, and community organizations that affect the acceptance and inclusion of PWD (Simpican et al., 2015).

It is important to include processes of community-based disablement within rehabilitation frameworks due to the circular relationship between how goals are conceptualized, ways
interventions are designed, and locating shared experiences of oppression (Farrell, 2008; Miles, 2002). The CBR framework is primarily focused on individual progress and improvement (see the CBR Matrix in Figure 1); therefore, it is crucial service providers acknowledge and appreciate societal barriers. The quality of services civil servants provide has been linked to their preconceived attitudes related to disability (Bailey et al., 2001; Gendle & Woodhams, 2005; Laan et al., 2013). Widely held notions of disability influence the day-to-day lives of PWD and their opportunities, yet with few exceptions research has not examined the beliefs and attitudes of Sri Lankans regarding disability. Of those exceptions, none have focused on how societal attitudes impact the perceptions and rehabilitation experiences of PWD themselves (Fernando et al., 2010; Hettiarachchi & Das, 2014; Higashida, 2016).

The aim of this research was not to explicitly critique the concept of CBR (Campbell, 2011; Kalyanpur, 1996; Twible & Henley, 1993). Yet, in the process of understanding CBR in practice and how WWD in the global South experience it, the results show clear issues with the current WHO CBR framework of intervention. Glaring gaps exist in the framework’s conceptualization and recommendations related to disability intervention, as well as the actualization of the model in Sri Lanka. As argued throughout this dissertation, there is a clear need to overhaul and improve the WHO CBR framework by using local knowledge of PWD and a concomitant investment in programs that address sexism and ableism.

Overview of Sri Lanka

Sri Lanka, previously known as Ceylon, is an island nation off the southeastern tip of India. Like many countries in the global South, Sri Lankan experiences have been shaped by over 400 years of Western dominance (Panikkar, 1965). Partial colonization of the island began with the Portuguese from 1505-1656, followed by the Dutch from 1656-1796 (de Silva, 2002).
The British took the coastal regions from the Dutch in the late 18th century, waging war against the Kandyan Kingdom interior to gain complete control over the island (Sivasundaram, 2007). British imposition lasted for 152 years and marked the first time in over 600 years the island was under one rule (Peebles, 1990). Ethnic-related turmoil was exacerbated by colonial imposition in Sri Lanka and occasioned lasting impacts (McConnell, 2008; Nithiyanandam, 2001; Peebles, 1990; Rogers et al., 1998). Rapid decolonization began after WWII and former colonies quickly became independent countries (Kalyanpur, 1996). When the country was renamed in 1972 the new constitution designated Sinhala as the only official language and Buddhism the prominent religion (Rogers et al., 1998).

Sri Lanka has a unique historical context related to the complexities of the “ethnicization of identities” during British colonialism (Thirangama, 2011, p. 111). The relationship between religious and ethnic minorities and the government’s long history of Sinhala-Buddhist nationalism is noteworthy (Keyes, 2016; Nithiyanandam, 2001; Rogers et al., 1998). In the 1980s, ethnic tensions rose and Sri Lanka became embroiled in a protracted ethnic civil war (1983-2009). In 2015, the government opened previously inaccessible northern and eastern regions to journalists and researchers (UN, 2015). These are areas reported to have high rates of disability and poverty (UN, 2018). During the war, conflict regions in the north and east were closed to virtually everyone. The conflict prevented outside assessment both from the local government (Department of Census and Statistics, 2014) as well as the international community (UN, 2015). The 2015 presidential election occasioned expectations of a shift away from infrastructure development toward investments in strengthening human capacities in areas of health and education (de Silva, 2016). The prospect of more accurate data, and the potential for
increased prioritization of human development projects, was promising. The extent of the actualization of these expectations is unknown and have likely shifted with the 2019 election.

The World Bank Group (WBG) estimates Sri Lanka’s population is over 21.7 million (2019). The Department of Census and Statistics (DCS) classifies the majority of the population as living in rural areas (77%) (2014, p. xi) although the current definition of “urban” has been criticized as being too narrow (Weeraratne, 2016). The “rural sector” is defined by what it is not. It is not an “urban sector” administered by a municipal or urban council—legislative bodies that govern first and second tier municipalities; nor is it an “Estate sector” area—plantations of 20 acres or more that have 10 or more resident labourers (DCS, 2010, para. 4). Local assemblies govern the rural sector of third and fourth tier areas (Samarasinghe & Samarasinghe, 1998).

Classifications aside, existing research notes a general lack of resources, especially in rural war-affected areas (Ayadurai & Sohail, 2006; Fernando et al., 2003; Muttiah et al., 2016) and in areas of high poverty (de Silva, 2016). The Central Bank of Sri Lanka (CBSL) reported the “Sinhalese” ethnic group comprised 74.9% of Sri Lanka’s population, with the remaining identified as “Sri Lankan Tamil” (11.2%), “Indian Tamil” (4.1%), “Sri Lankan Moor” (9.2%), or “Other” (0.5%) (2015, p. 1). The same CBSL report estimated religious composition as: “Buddhist” (70.1%), “Hindu” (12.6%), “Muslim” (9.7%), “Christian” (7.6%), or “Other” (0.5%) (2015, p. 1).

WBG classifications are considered by many in international development to be associated with a country’s overall level of welfare. The WBG (2019) recently re-classified Sri Lanka from a LMIC with a 2017 Gross National Income (GNI) of $3,840 USD (Rs.576,000 LKR) to an UMIC economy with a GNI of $4,102 USD (Rs.615,300 LKR). LMIC designations are given to countries with a GNI per capita between $1,026 and $3,995 USD (WBG, 2020). The
CBSL website reported a lower per capita income of Rs.666,817 LKR ($3,473 USD) (CBSL, 2018). The remainder of this dissertation details currency in the form of Sri Lankan Rupees (Rs., LKR). During fieldwork from 2016 to 2017, the exchange rate was around Rs.150 LKR to $1 USD. The LKR has since declined in relation to the USD, with a rate of around Rs.190 LKR.

Although GNI designations do not consider inequalities in income distribution, the classifications are important and impact international trade as well as aid allocation policies from both private and public sectors (Glennie, 2011). In fiscal year 2017, Sri Lanka graduated from the WBG’s International Development Association support program, a program aimed to reduce poverty through loans and grants (WBG, 2019), and received transitional support through 2018-2020. Mundy and Verger (2015) argue the International Development Association was created out of concern emerging from the United States that communism would advance in post-colonial nations and disrupt the stability of the existing world system. The authors note many borrowers will soon graduate into middle-income countries that are soon to be home to the majority of the world’s poor. These economic transitions occasion a recent turning point in Sri Lanka’s relationship with international financing and development programs and corresponding impacts should be investigated in future research.

The UN Human Development Index is another international framework used to symbolize a country’s development status. The Human Development Index is a summary measure of a country’s average achievement across three dimensions: life expectancy, level of education, and income. Sri Lanka ranks among the top in the South Asian region and has risen considerably since 2002 (Mendis, 2004). The country’s life expectancy at birth is higher than many other South Asian countries (WBG, 2019). This fact may be attributed to a tax-financed public health system (Withanachchi & Uchida, 2006). The government is implementing health-
system reforms to reach universal coverage in the near future and is among a handful of Asia-Pacific countries noted to have achieved universal secondary education (UN, 2018).

**Disability Measured**

Disability in Sri Lanka is legally defined by the “Protection of the Rights of Persons with Disabilities Act, No. 28 of 1996.” Article 37 states "person with disability means any person who, as a result of any deficiency in his physical or mental capabilities, whether congenital or not, is unable by himself to ensure for himself, wholly or partly, the necessities of life.” The National Policy on Disability for Sri Lanka (2003) argues the legal definition of disability is reasonably broad enough to encompass “both the medical and socio-economic aspects of disability” and notes disability must be understood in relation to social constraints and environmental factors (Ministry of Social Welfare, 2003, p. 9).

In 2012, the DCS conducted Sri Lanka’s first island-wide census after three decades of conflict (DCS, 2014, p. vii). The DCS survey used a 5% sample of citizens over five years of age and defined disability as, “a functional difficulty in at least one or more domains namely as vision, acoustics, mobility, cognition, self- care and communication” (DCS, 2014, p. xi). More women than men, 9.5% and 7.6% respectively, reported having the “functional difficulties” listed on the survey (pp. 100-101). These results are lower than expected (WHO, 2018) but are much higher compared to a 2001 DCS report stating less than 2.5% of the population had a disability; unsurprisingly, the report notes homeless populations and people living in the northern and eastern regions could not be counted (DCS, pp. 1-3).

In response to these statistics, an International Labour Office AbilityAsia study claimed statistics on the prevalence of disability were “unacceptable” and “gross under-estimates” (Mendis, 2004, pp. 11-12). The country is expected to have high levels of disability due to an
aging population and decades of civil war (Peiris-John et al., 2014). Low estimates of disability may also be attributed to the types of disability screening methodologies used (Campbell, 2009, 2011; Sabariego et al., 2015); the inaccessibility of northern and eastern areas due to prolonged civil war (DCS, 2014; Hyndman & De Alwis, 2003); and difficulties associated with conducting an island-wide field-based survey (DCS, 2014). For years, researchers and activists have underscored the need for accessible and disaggregated data related to the status of disability in the country (Peiris-John et al., 2014; Mendis, 2004).

In contrast to low disability estimates, a DCS and Ministry of National Policies and Economic Affairs field-based survey conducted in 2014 showed high numbers of chronic illness. Using a sample of 25,000 housing units throughout the country the DCS report found “17.8 percent of the total population has some kind of chronic illness” (p. 13). The survey included 10 categories of chronic illnesses: “high blood pressure, diabetes, asthma, arthritis, heart disease, mental illness, stroke/paralyzed, cancer, epilepsy, and other” (DCS, 2016, p. 13). The report estimate more closely aligns to the expected prevalence of disability; however, narrowly defining disability as a health issue risks falsely equating disability with poor health, and poor health with disability (Lord et al., 2012). As discussed, due to the war, conflict regions in the north and east were not often monitored. In light of limitations, it is still useful to critically examine published statistics and information. Appendix B shows national data estimates of WWD in Sri Lanka. It should be noted the low percentages, especially those in the eastern and northern regions, likely underrepresent a high prevalence of disability.

**Rights-claims, Health Systems, and the Emergence of CBR**

In a landmark judgment, the Supreme Court (SC) this week ruled that the Fundamental Rights (FR) guaranteed by Article 12 (1) of the Constitution to persons with disabilities had been violated by the State and its agencies. […] A further direction was issued to the respondents to initiate disciplinary proceedings where appropriate against public officers
who are found to have granted approvals or issued certificates of conformity in breach of and/or in violation of and/or in disregard of the provisions of the Disabled Persons (Accessibility) Regulations No. 1 of 2006. (The Sunday Times Sri Lanka, 2019, April 21)

The headline reads “State’s disregard for the disabled invites SC censure.” The article was published on the same day as the “Easter Bombings” in Sri Lanka that killed 259 people. The tragic events of April 21, 2019, overshadowed the information contained in the newspaper.

The article detailed the Supreme Court decision that the constitution was violated, there is widespread government non-compliance with accessibility regulations, and the limit for compliance had expired. Dr. Ajith C. S. Perera was the petitioner on the case. An activist for many years, he pursued legal recognition of non-compliance regarding legislation. His petition states:

All public buildings and public places must provide access facilities for persons with disabilities which are in compliance with the aforesaid regulations, should be constructed in a manner which complies with the aforesaid regulations and that newly constructed public buildings should not be issued a certificate of conformity unless they are constructed in compliance with the aforesaid regulations. (Perera v. Minister of Social Services and Social Welfare and the Chairman of the National Council for Persons with Disabilities, 2019, p. 5)

Sri Lanka’s “Protection of the Rights of Persons with Disabilities Act, No.28 of 1996” proclaimed many years ago that all newly constructed public buildings and structures were to be built with a plan adhering to the accessibility regulations. The legislation also stipulated all existing public places/buildings, and places offering common services, be made accessible within three years (Ministry of Health & Directorate for Youth, Elderly and Persons with Disabilities, 2013). As the recent Supreme Court case details, laws intended to improve physical access to public places have failed at the expense of recognizing Sri Lankan’s fundamental rights. The British instituted a government system that remains fragmented, especially in relation to accountability and the provision of social services. Evidencing this, the recent Supreme Court ruling cited the duties of eight respondents to the case: 1. Minister of Social Services and Social
Womens experiences of disability and CBR


Across time and place, PWD have been relegated to lives removed from societal interaction—denied human status, citizenship, and basic rights (Siebers, 2013; Silvers & Francis, 2013). Fernando and colleagues (2003) note that British rule shaped the present-day health services into a “western” system. According to de Silva (2002), many years of British occupation introduced the “Ceylon Lunacy Ordinance,” promoted the incarceration and institutionalization of people with mental illness, and weakened Sri Lanka’s complex system of medicine and folk practices (p. 67). However, according to Miles (2002), Buddhist asylums for PWD in Sri Lanka predate Christianity. During British colonization, Sri Lankan institutions for PWD were heavily criticized as insufficient and overcrowded (Mills & Jain, 2009).

Conceptualizing Community-based Develop/Disable-ment

Community-based Rehabilitation (CBR) Research and a Social Model of Disability. Most government agencies treat disability using either a custodial or a medical-related model (Chataika & McKenzie, 2016). In contrast, nongovernment organizations (NGOs) and international nongovernment organizations (INGOs) claim to use a more contextually-based understanding of disability (WHO et al., 2004). Many organizations have mission statements aimed at promoting social inclusion. The WHO developed the framework of community-based rehabilitation (CBR) in order to increase services for PWD (WHO et al., 2004). For decades,
CBR has been promoted globally in developing economies to help PWD (Finkenflügel et al., 2005; Helander et al., 1983). CBR is a model of intervention that aims to sustainably address “attitudinal, institutional and physical barriers that may be present in the community” through the active involvement of PWD and their families (WHO et al., 2010b, p. 4).

CBR aims to improve individual outcomes across five sectors: health, education, livelihood, social, and empowerment (WHO et al., 2010f). These are described in detail in Chapters 3-5 and are represented in Figure 1. The WHO CBR Empowerment Guidelines describe one aspect of empowerment as “being capable of fighting for one’s rights, and being recognized and respected as equal citizens and human beings with a contribution to make” (WHO et al., 2010b, p. 1). This statement encompasses the two primary objectives of CBR. First, to ensure individuals with disabilities have access to services and opportunities, and second, to recognize the community’s responsibility to remove barriers to participation through sustainable community-based changes (WHO et al., 2004).

An often overlooked, and potentially exploited, defining feature of CBR is PWD must have an active role in the rehabilitation process (WHO, 1994). For example, the model suggests CBR programs promote the development of disabled people’s organizations (DPOs) in order to transfer their knowledge and skills to other PWD and the larger community (WHO et al., 2004). A failure to include PWD in the conceptualization of the rehabilitation process has occasioned frameworks and programs that preclude sustainable community-based change efforts. Such programs might direct resources toward educating general populations and increasing universal access within communities.

Discussions around the inclusion of PWD in CBR are often framed using an empowerment discourse. While it sounds progressive, empowerment models in theory and
practice may instead be signposts for maintaining the neoliberal status quo (Chaudhry, 2019). The foundation of a neoliberal discourse holds social progress comes from a deregulated and privatized market, effectively dismantling welfare provisions and shifting divisions of labor (Harvey, 2005). In the context of this research, an empowerment discourse may be a symptom of an ablest framework fueled by neoliberalism that places the burden of care and the burden of change on PWD and their families (Chaudhry, 2019). The design of the WHO empowerment framework makes the individual responsible for everything and the collective “public” responsible for nothing.

The majority of CBR design, practice, and research ignores the positionality of its recipients. The current template of community-based programs, using a framework that ignores “capitalist and patriarchal cultures,” upholds a masculine definition of labor that dismisses the hidden costs of women’s labor (Mohanty, 2003, p. 151). Questioning who is responsible for change is central to the current research within a context of CBR programs that uphold neoliberal characterizations. Throughout the chapters, notions of neoliberal ideals of progressiveness are evident in both the women’s interviews and the contextual interviews from program leadership. This finding is not surprising in light of a CBR matrix that fails to demand public commitments to improved access and social investment. Instead, programs focus almost exclusively on individual markers of progress. Rehabilitation and development literature often fails to take legitimate critiques seriously, and ignores the impact global approaches of rehabilitation can have on the dissolution of local economic, social, and cultural knowledges (Kalyanpur, 1996).

Disability scholars argue there is an important connection between imperialism and the WHO’s dissemination of technology in pursuit of “global health” (Amrith, 2006; Campbell, 2011; Erevelles, 2011). Histories of “health” programs in relation to forced labor and European
domination over colonized “uncivilized” populations are significant (Panikkar, 1965). The WHO governs discourse on international health policy and “carved a space, between American hegemony and the aspiration of Asian nation-builders, for the practice of biopolitics” (Amrith, 2006, p. 14). Amrith locates the problem within humanitarian narratives that fail to critique global health and the expansion of Western medicine, omissions that obscure histories of violence and colonization. Explicit relationships between the colonized and colonizer in post-colonial states may be less clear but an imbalance of power is evident in how “the institutional, intellectual and epidemiological legacies of the colonial medical past continued to shape and constrain post-colonial debates and policies on public health” (p. 15). Almost a quarter century ago, Zambone and Suarez (1996) noted:

We often assume that our models must be exported and replicated to insure that adequate services are available to children and youth with special needs, but rarely assume that we can learn a great deal from the “developing” countries. (p.3)

By centering the experiences of WWD in CBR programs in Sri Lanka this research critiques the WHO intervention framework. Failure to acknowledge important facets of economic and political domination shaping development frameworks continues to perpetuate inequities. The experiences of WWD are presented as valid and important sources of knowledge that must inform CBR theory and practice moving forward. Findings presented in Chapters 3-5 offer a different perspective regarding rehabilitation and provide recommendations for what we as a global society must do on a community level.

Critiques of how we value and construct knowledge are not new. Yet, rehabilitation research often fails to document local systems of sociocultural knowledge and the perspectives of PWD within the context of their communities. The failure of society to respond to social inequalities that continue to marginalize groups of individuals is a global issue that permeates
states regardless of their level of resources (Horner-Johnson et al., 2014; Libal & Harding, 2015; Silvers & Francis, 2013). CBR programs are intended to be more empowering than past segregated forms of rehabilitation (Cleaver & Nixon, 2014; WHO, 1994; WHO et al., 2010f). However, few CBR-related studies use methods that incorporate the perspectives of PWD (for notable exceptions see: Bualar & Ahmad, 2009; Chappell & Johansmeier, 2009; Gartrell, 2017; Gulati et al., 2011; Samararatne & Soldatic, 2015). It will not be possible to implement sustainable community-based change without a major shift toward inclusion. An critical paradigm shift is required to broaden the scope of existing development frameworks aimed at improving inclusion and access for PWD. Disability-related research and practice must evolve away from prioritizing the interests of funders and I/NGOs to instead foster programs and practices that privilege the perspectives of PWD, specifically in the global South (Kuipers & Sabuni, 2016; Meekosha & Soldatic, 2011; Meyers, 2014).

CBR, Disability, and Gender in Sri Lanka. Thus far, I have discussed aspects of disability in Sri Lanka without incorporating gender. As stated earlier, WWD have a unique and important (Naples & Gurr, 2014). This section raised questions related to systematic issues that occur within a framework that is reliant on individual responsibility while at the same time neglectful of the social position of the people it aims to serve. Globally, women hold a subjugated position within society relative to men, and Sri Lanka is no exception. The marginalization of women is evident throughout this dissertation, as are the multiplicity of ways isolation occurs at the intersection of gender and disability status. The crux of this research questions how a framework of rehabilitation can expect such personal responsibility for change while ignoring experiences of systematic sexism and ableism, disempowering forces that must be acknowledged and addressed.
CBR as a framework promotes programs of intervention where PWD advocate for and assist each other while having an active role in the rehabilitation process alongside their families and communities (WHO, 1994). Adopting a feminist view of gender and disability, one that locates qualitative experiences of the less powerful in society, assists us in critiquing interventions that place large amounts of social and economic responsibility on marginalized groups. In CBR, this is characterized through over-burdening PWD and their families (Chaudhry, 2019; Erevelles, 2011). The responsibilities of PWD and their families are often accompanied by a failure of development programs to include them in the designing of community-based services (Kalyanpur, 1996). An artifact of this exclusion is the participation of PWD within their communities is one of the least researched aspects of CBR (Finckenflügel et al., 2005). The absence of research promoting the perspectives of PWD in the development, implementation, and/or evaluation of CBR programs and research fundamentally alters the meaning of CBR and ultimately fails to produce a meaningful contribution.

Very few studies have been conducted in Sri Lanka with regard to the actual experiences of disabled women, or the social construction and consequences of being WWD. Research on disability in Sri Lanka has appeared in the fields of sociology, education, psychology, and social policy, with a focus on those serving the disabled population. For example, studies related to Sri Lankans’ attitudes toward disability have found biases held by special education teachers (Hettiarachchi & Das, 2014) and healthcare providers (Fernando et al., 2010). Both correlated negative beliefs with a general lack of exposure and training, but neither examined how stereotypes and stigma specifically influence the sociocultural beliefs of their respondents, or how those beliefs impact PWD. These omissions are important as increased professional
exposure to PWD alone would not address deeply held stigma related to societal beliefs of karmic retribution prevalent in South Asia.

Samararatne and Soldatic’s (2015) qualitative examination of women’s experiences of disability in rural and war-affected areas, and de Mel’s (2016) research related to disabled soldiers and masculinity, incorporate Sri Lankan perspectives related to disablement. Both found men and women encountered physical inaccessibility with regard to using public transportation and public bathrooms (de Mel, 2016; Samararatne & Soldatic, 2015). In addition to physical barriers, research on disability in Sri Lanka has uncovered stigma-related barriers concerning access to marriage (Ministry of Social Welfare, 2003; de Mel, 2016), education (Hettiarachchi & Das, 2014; Liyanage, 2017; Wickenden & Elphick, 2016), healthcare (Fernando et al., 2010), and employment (DCS, 2014; Tudawe, 2001). Further, WWD in Sri Lanka encounter considerable obstacles to their social and economic stability related to their class, gender, and disability status (Kandasamy et al., 2017a; Mendis, 2004; Samararatne & Soldatic, 2015; Tudawe, 2001). Women experience a subjugated position in society both personally and politically and have low levels of equality in employment and political representation (UN, 2018). In particular, participation for WWD in public life is shaped and constrained by beliefs surrounding gender, ethnicity, class, and disability status.

In sum, literature related to CBR has found programming in the global South does not address multiple complex sociocultural issues that frame women’s lives, nor does it employ a social framework of disability that is needed to understand experiences of community-based disablement. This deficit suggests CBR has mostly failed in the primary objective of recognizing the responsibility of communities to ensure access and opportunities for PWD. Thus, CBR-related research and practice must first prioritize the documentation of the social nature of
disablement and in doing so specify the socio-cultural barriers PWD encounter. Second, it must
attend to the ways participants of CBR programs occupy multiple social categories and may
therefore be multiply marginalized. Relevant literature related to Sri Lankan context is discussed
throughout the chapters. There is a need to document ways gender, culture, and geographic
location impact the development and experiences of WWD in Sri Lankan communities
(Hyndman & De Alwis, 2003; Mendis, 2004; Samaratne & Soldatic, 2015; Zaviršek & Herath,
2010). In applying a broad framework, this work aims to improve research, practice, and
advocacy by attending to aspects of community-based disablement.

Research Questions

1. How do WWD describe experiences of participating in CBR programs in Sri Lanka?
2. How do environments: social (i.e., attitudes about gender and or disability) and built (i.e.,
   transportation systems, buildings) affect the participation of WWD in CBR?
3. What are the stated needs and goals of WWD in CBR? Do they perceive they have
   influence on the CBR services and programs?
4. How do prevailing societal and personal beliefs about disability influence the
   participation of women with disabilities in CBR programs in Sri Lanka?

Dissertation Preview

In the following chapters, I discuss aspects of specific historical, economic, and cultural
locations of WWD in Sri Lanka. This dissertation considers the social and political contexts
shaping CBR in a postcolonial state with a legacy of social service systems developed through
colonial administrations and global capitalism (Chaudhry, 2019). Examining intersections of
gender and disability locates issues that occur when a focus on individual intervention
overshadows the need for structural improvement and community development (Boyce &
Ballantyne, 2000, p. 73). I endeavored to incorporate the data collected and presented in this dissertation in a way that closely attends to “ongoing effects of colonialism, to local hybrid practices, and subaltern strategies of resistance” (Senier & Miranda-Galarza, 2016, p. 401).

Those working in the field of disability must identify specific social locations and conditions that accompany gender discrimination, geographic isolation, and economic disenfranchisement. In this dissertation, human variation is not an underlying disabling problem. Society is. While there are contemporary shifts away from the medical model of disability in some academic disciplines, these conceptual changes are just the tip of the iceberg in fields where practice often precedes research and theory. This research shows development programs have to first address various forms of discrimination such as ableism and sexism to ameliorate systemic inequities. Research and practice must prioritize a social understanding of disablement, especially as it relates to women’s experiences of marginalization in society.

To continue to only “treat” disability creates and maintains large-scale disparities across numerous sectors and ignores social and political issues perpetuating the systematic exclusion of difference. Pervasive beliefs around gender and disability held by society—including PWD, families, community members, and service providers—must be identified before we can understand larger cultural, political, and social barriers limiting the societal inclusion of particular groups of people (Blanck et al., 2006). The lack of inclusion and representation of WWD is problematic for multiple reasons: it ignores social, cultural, and economic barriers that marginalize WWD (Samararatne & Soldatic, 2015); maintains programs that may not be effective or meaningful for participants (Bualar & Ahmad, 2009); and fails to grant ownership of rehabilitation services to recipients (Gulati et al., 2011). The existing lack of experiential knowledge in the literature can be addressed via a theoretical shift that conceptualizes disability.
as a social construct, employs research methods that center and implicitly value experiences of disablement, and embeds that knowledge within a historical and contemporary societal critique.

In this chapter, I have presented the case for a ground-level examination of CBR services as they existed in Sri Lanka for women. In Chapter 2, I detail the ethnographic methods and qualitative approach taken. Primary research findings are detailed in Chapters 3, 4 and 5. Important deviations are noted in relation to the traditional five-component CBR matrix (WHO et al., 2010f), especially in relation to gender, class, family status, and geography. Ways WWD navigate resources and negotiate avenues of agency within their families, communities, and institutions are the primary focus. Finally, in light of the research presented, Chapter 6 argues for a fundamental shift in our conceptualization and implementation of CBR. The findings of this research support demands to re-examine program priorities, critique funding allocations, and utilize PWD-led evaluations.
CHAPTER 2. METHODS

…for feminist disability studies to make good its claims for transformative politics, it would have to expand its analytics from discursive interventions to a foregrounding of the materiality of structural constraints that actually give rise to the oppressive binaries of self/other, normal/disabled, and us/them. (Erevelles, 2011, p. 129)

This study used two subtypes of ethnographic methodology: participant observation and interviews. Participant observation and interviews are ethnographic methodologies used to gather data about a particular culture, setting, and shared social experience. I used these methods to center women’s experiences, examine perspectives of CBR program leadership when working with WWD, and to learn about the overall social context for WWD in CBR in Sri Lanka. Utilizing CBR programs as gatekeepers, sites of observation and interview recruitment, offered unique challenges and opportunities discussed in this chapter and throughout the dissertation.

Ethnographic Fieldwork

The research questions are exploratory and focused on gathering on-the-ground information related to experiences of gender, disability, and rehabilitation. The primary aim was to gather information related to how WWD describe personal goals and experiences of CBR programs, and to identify ways physical barriers and social beliefs about gender and disability impact their community participation. The best way to answer open-ended questions is through using methods that capture specific meanings held by people on the ground, and ethnography is best designed for accomplishing these tasks.

Ethnography is a method of field research where the investigator systematically documents and directly participates in everyday activities within in a particular setting. In experiencing ordinary activities, this method leads to data that “capture their social meanings” (Brewer, 2000, p. 6). Ethnography is important in the context of the current research as it occasions an in-depth and longitudinal examination of performing and observing routine
activities within the local socio-cultural context of Sri Lanka. Ethnography as a method is reliant on people’s experiences (Smith, 2005). I use both participant observation and interviews because they complement each other, and together they offer the most comprehensive way to answer the research questions. Participant observation allows for my experiences in the field to be systematically studied, and interviews document the narratives of participants in CBR.

**Participant Observation**

Direct involvement in the here and now of people’s daily lives provides both a point of reference for the logic and process of participant observational inquiry and a strategy for gaining access to phenomena that commonly are obscured from the standpoint of a nonparticipant. (Jorgensen, 1989, p. 9)

The first method, participant observation, involves collecting data through observation in natural settings. This method offers an additional dimension to the socio-cultural context of Sri Lanka and enriches the depth of inquiry related to the research questions. My participant observation within each CBR program was unstructured and informal in nature. The particular type of participant observation used may be classified as observer-as-participant. I ensured everyone was aware of my purpose and I actively engaged with people being observed, although I did not perform any direct CBR-related duties (Jorgensen, 1989; Kawulich, 2005). In the sections below, I detail the frequency, duration, and nature of my participant observation.

**Interviews**

The second type of data collection method used were semi-structured in-depth interviews. These were used to interview 46 WWD and 6 CBR leaders. Semi-structured interviews are a specific type of interviewing technique that entails flexible timing and sequencing while covering a list of interview questions. The strength of this format is that it narrows the interview content in order to focus on the research questions while maintaining a conversational tone during data gathering. Semi-structured interviewing allows for adapting the conversation in response to
each interviewee’s answers and needs. This openness provided space for new ideas and data that reflect information the interviewees deem important (Charmaz, 2006; Creswell, 2014). All interviews were completed using a face-to-face format. This interview style was advantageous when it appeared the women did not fully understand, or were not prepared to answer, a particular question the first time it was asked. An in-person format allowed for follow-up questions on all sides related to clarifying the meaning of particular questions (Bernard, 2006).

Women discussed multiple subject matters, sometimes topics initiated by them appeared to make them uncomfortable. I monitored their reactions alongside the interpreter to ensure they wanted to continue. I discuss the interview process in much greater detail in the sections below.

These two methods, participant observation and interviews, combine to produce data that complements the other and operationalizes the overall objectives of the research. Together, they strengthen the quality of data in order to address the aims of this research—particularly the gathering of multiple perspectives within CBR programs while simultaneously and systematically gathering observational data to contextualize their experiences within the environment over time. For example, I observed day-to-day interactions at the CBR sites and then interviewed those involved in the programs. These methods, gathering data from multiple perspectives during fieldwork, highlight tensions existing between communities, service providers, WWD, and the research process itself. I discuss reflexivity later in this chapter. Reflexivity involves examining details of how my gender, ethnicity, and nationality may have impacted aspects of entering and maintaining field sites; managing the data collection process as well as expectations of exchange and reciprocity; and departing from each field site.

This research focuses on WWD. I interviewed 46 disabled women who were recruited through five CBR sites. All interviewees and all field sites are identified using pseudonyms. The
sites and interviewees are discussed at length below. For now, I would like to add a note addressing the category of WWD. In order to identify and recruit WWD for interviews, I relied on community-level perceptions of disability (Mendis, 2004). Specifically, WWD in the current research were recruited based on their involvement in CBR programs. The category WWD in this research is “discussed in terms of disability politics, not because of any essential similarities among them, but because all have been labeled as disabled or sick and have faced discrimination as a result” (Kafer, p. 11, 2013). The identification of women with disabilities, and the use of the acronym “WWD”, is not meant to generalize or indicate a discrete category or fixed group of women (Kanter, 2013). The use of WWD to refer to the participants in this research is for brevity. It should be noted some women said they are not disabled, expressing disability as either a social construct imposed on them or an internal state of mind that could be changed with proper counseling and guidance. While most women involved in this study presented with visible physical impairments, others discussed physical disabilities that were not visible or were concealed from public view. All shared their unique perspectives and experiences.

Situating Ethnographic Research

As discussed in the introduction, scholarly articles related to CBR often center experiences of teachers, parents, caregivers, and social workers as respondents, instead of PWD themselves. The few that incorporate PWD as main informants often use male perspectives. These gaps solidified my desire to focus on gathering more information about women as service recipients within CBR, and the ways CBR interventions are represented in research and reality. I also aimed to present women interviewed for this research as agentic in their own lives—not as victims of circumstance to be pitied (Mohanty, 2003). Social science research posits questions and employs methods that access ways people understand their own capacity to act in particular
settings within their multiple and fluid positionalities (Maynes et al., 2008, p. 23). This technique further strengthens the case for methods centering women and their lived experiences.

There is a lack of data pertaining to disability in the global South and the ways women experience disability in these understudied contexts. While aiming to address these gaps, I found WWD were “the silent majority living at home” (Arunadhan, leader of the Northern Vocational Community Center). The isolation of WWD, and their lack of visibility, created challenges during fieldwork that are discussed throughout this dissertation. Thus, I use the methods detailed in this chapter to begin to address this problem, bearing in mind that groups such as WWD are systematically excluded from forming knowledge that claims to speak about and for them (Campbell & Gregor, 2004; Kanter, 2010; Naples & Gurr, 2014; Siebers, 2013).

Fieldwork

How I Came to Study in Sri Lanka: Background and Access

I chose to base my research in Sri Lanka for multiple reasons. As discussed in the introduction, I love living, working, and learning about ways individuals within societies live. My background in designing individual behavioral interventions for PWD in America, combined with my experience in international development at the organizational level within a residential treatment center in the Philippines, led me to investigate community-based intervention programs for PWD. I sought to study the WHO framework of CBR after being exposed to the real-world limitations of both individual and institutional interventions. In mostly contained service settings, both in the US and the Philippines, I witnessed allocation of money and resources away from the direct benefit of PWD. I had high hopes for the community-based approaches detailed in the international development literature. CBR is arguably the most prolific, yet still under-researched community intervention framework for PWD.
In 2015, an online search of WHO CBR programs led me to a WHO website highlighting their work related to CBR and the Model Disability Survey, a large-scale data collection effort related to measuring disability prevalence in Sri Lanka. There was an email address at the bottom of the page for someone working within the WHO. I wrote to and received a reply from a public health researcher based in Europe. She assisted in conducting the survey in Sri Lanka, and introduced me to a Sri Lankan community leader via email. I sent a follow up email to the community leader explaining my research interests and my goal to secure funding from a government agency to conduct my research. To my surprise, I received a very enthusiastic reply related to my research topic as well as assistance in locating an institutional affiliation needed for my grant application. A search on the history of CBR led me to one of the original 650 page WHO publications on the topic, a manual focused on training laypersons to safely and efficiently deliver rehabilitation services to underserved individuals with disabilities (Helander et al. 1983).

Sri Lanka has an almost hundred-year history of community-level field-based “health units” (Fernando et al., 2003). CBR materials were often distributed by ministries of health and disseminated to individuals and families through local supervisors, frequently local health workers (WHO, 1994). The WHO notes several sectors, e.g., health, education, social, and labor, are all involved in CBR and must work together (WHO, 1994). Yet, evidence of multi-sectorial representations in CBR are not common in the literature, and many countries do not have the infrastructure established for communication and coordination between social, health, educational and vocational sectors (Kalyanpur, 1996).

My research location and focus were solidified by the coincidence of not only finding a CBR expert willing to provide mentorship, but one who was also Sri Lankan. Over the course of two years (2014-2016), I crafted my Fulbright grant proposal and, in doing so, my dissertation
research project. In November 2016, I flew to Sri Lanka as a Fulbright Student Researcher on a nine-month grant. If I had not received funding, I would have been required to self-fund my research as my comprehensive exam, dissertation proposal, and research connections were all completed and very much focused on Sri Lanka. I realized later in my tenure as a student-researcher affiliated with the Fulbright Commission in Sri Lanka that I was provided with an array of financial and professional benefits. The grant covered only my personal expenses as a student researcher (not interpretations, translations, or other research-related expenses), but it was possible to live within the allotted monthly stipend. In addition to financial assistance, the local Fulbright Commission staff served as mentors and advocates for my research project. I also learned, after returning to the United States, many of my non-Fulbright peers personally struggled to navigate the bureaucratic channels in order to secure the proper visas and research permissions that were provided easily to me through my grantor.

Even with support, local ethical permissions for research took longer than expected. At one point, there was some miscommunication and I was asked to provide a large sum of money to get official ethics permissions. I consulted with the Commission, who quickly assisted and advocated on my behalf. Four months after arriving, in March 2017, I secured all ethics approvals. I was mainly based in Colombo in the months prior to receiving approval. Colombo, the economic capital of the country, is located on the west-central coast. There, I learned more about Sri Lankan culture, participated in weeks of Sinhala language courses, networked with embassy and non-government professionals, and attended training sessions hosted by academic and community organizations related to current affairs. During that time, I also visited multiple CBR organizations that were not included in this research because they were either ineligible to
participate based on the demographics of their program recipients, or site leadership did not return my requests for additional meetings.

I found a CBR program willing to host my research seven months into the nine-month grant. The slow pace of my research is not an uncommon story when conducting fieldwork in other countries, and a significant contributor to the delay of identifying field sites was my lack of local language proficiency. The Fulbright grant provided six weeks of Sinhala courses, although it was just enough for me to express basic needs and greetings. Additionally, because it was very difficult to locate women interpreters who could travel with me to remote field sites, the first two interpreters I hired were male. The work was intermittent and I paid them around Rs.3,000 LKR per day, in addition to providing food and housing costs when travel was required. Working with male interpreters presented additional challenges that are discussed later.

My goal is to anchor my methods and analyses within communities of WWD in Sri Lanka. This positioning of my data is an effort toward an inclusive decolonial research paradigm that considers ways to promote social justice (Mohanty, 2003). As a researcher, I gathered data that locates Sri Lankan women as strong, agentic, resisters—all of them operating against patriarchy within “a common context of struggle” (Mohanty, 2003, p. 143). My aim for this dissertation is to present this work as a product of solidarity, full of non-static struggles and collective differences. I optimistically intend to simultaneously critique and inform development bureaucracies in order to create a space for praxis through theoretical reflection. I hope this action will clear the way for the wide-spread, critical, and effective engagement of those of us concerned with dismantling the continuities of social struggles (Enslin, 1994). Here, the problem is not disability, it is the social process of disablement that is often ignored in development research. This vision carries this work forward.
This dissertation is the product of 13 months of field observations and 52 interviews. Even though I spent considerable time in the field, I am an able-bodied Western white woman who observed and interviewed Sri Lankan CBR leadership about their programs and Sri Lankan women about their experiences of disability. It is certain my presence and place of privilege occasioned particular events and reactions. My questions may have elicited responses that considered my class and social position in society compared to if the questions were asked by a Sri Lankan. It was also very apparent that the gender, interview style, and English language proficiency of the interpreters I worked with influenced the quality of the data I collected. These issues are discussed in-depth throughout the dissertation and in a section on reflexivity below.

**Interpreters**

The majority of people in Sri Lanka speak Sinhala or Tamil. I do not know these languages. Thus, I had to locate interpreters to assist me with data collection. The research assistants I hired helped with recruitment and scheduling of interviews. They primarily interpreted interview questions from English into either Tamil or Sinhala, and also conveyed the women’s responses into English. One of the original goals at the outset of my research was to locate and hire Sri Lankan women as assistants to work with who lived in the same regional areas as the field sites that agreed to host my research. The interpreters had to have a level of English proficiency required to satisfactorily pass the University of Connecticut’s rigorous ethics certification exam, as well as the ability to communicate the aims of the research conversationally. I also hoped the interpreters I hired would be able to transcribe, by typing on a computer, the Sinhala/Tamil audio portions of the interviews into their native language. I was unable to locate anyone who could type the women’s words into electronically-editable text files of Sinhala or Tamil script.
After leaving Sri Lanka, I hired three Sri Lankans to complete the second step of pre-recorded audio translation. They listened to excerpts of the previously recorded interview audio and transcribed what was spoken in Tamil/Sinhala into English text. This is a tedious and expensive process, nevertheless 17 out of 46 translations have been completed (2 Tamil and 15 Sinhala). This second step of translations was funded in part by a grant for graduate student researchers within my department. Months later, peers working on research in Sri Lanka informed me a more accessible way for translators to work on this type of project might be to request spoken instead of typed translations, i.e., to submit their translations orally instead of textually. Although this potential third step of translation is not examined in this dissertation, it remains an interesting area of inquiry. This reconceptualization of working with translations during fieldwork may indicate a more preferred platform of communication for translators, and potentially increase data quality and efficiency.

Interview audio that has not gone through the second step of translations is indicated immediately following the quote by an asterisk symbol (*). This symbol indicates the quote has only gone through one round of translations: the real-time Tamil/Sinhala interpretation into English during the interview. These quotes are words spoken in English by the interpreter during the interview to communicate the answers of the women being interviewed, and have been slightly edited as such.

In total, I hired four local interpreters to communicate intent and logistics effectively, to inform me about the area’s customs and expectations, and to interpret during interviews. I tried for months to locate women interpreters to work with. Every time I engaged with a potential contact, once they asked for family permission to travel and work with me, an unmarried woman, they, also unmarried women, were denied. This occurrence signaled significant restrictions
relating to women’s mobility in Sri Lanka. Eventually, I located two male interpreters while at the first three CBR field sites: the Northern Rehabilitation Center (NRC), Northern Vocational Community Center (NVCC), and the Southern Rehabilitation Center (SRC). Finally, I identified and hired two women to work with at the remaining two CBR field sites: the Central Community Organization (CCO) and the Eastern Community Based Organization (ECBO). These CBR organizations are introduced in more detail in the next section.

The first male interpreter I hired was located through a friend of a friend’s mother’s friend’s daughter. He was a classmate of one of the daughters living in the house connected to the annex I rented. He was very adept at recruiting, organizing and planning the logistics of interviews, and mediating between site leadership and stated research goals. He was not the strongest interpreter during interviews. He was a medical student, so was not used to the type of interviews this research called for: extensive open-ended questions with long silences. This required I rephrase questions to be more general when working with him. I also scheduled additional meetings to reiterate that for this type of research the answers women give to specific questions are just as important as allowing them time and space for personal elaboration.

We conducted the first set of 10 interviews at two field sites, the Northern Rehabilitation Center (NRC) and the Northern Vocational Community Center (NVCC). These interviews were shorter on average compared to the other three sets of interviews. This brevity is likely due to many combining factors: it was the first group of interviews I completed; I hired a male interpreter to interview women about potentially gender-sensitive topics; and, as a medical student, he had not conducted qualitative interviews prior to working with me. This lack of experience was supplemented by his assertiveness and ambition. After weeks of encountering
difficulties in recruiting women interviewees through NRC he quickly identified and set up a meeting with Arunadhan, the leader of NVCC, another northern region CBR program.

During the last half of my fieldwork, I was able to identify two Sri Lankan women to work with. Both did not have fathers and therefore they were not required to seek the typical permissions in order to travel and work with me. The first was a Sinhalese information technology undergraduate student I met at an acquaintance’s party. We became good friends, and were roommates prior to her working with me on this project. I hired her during semester break to interpret for all 11 Sinhala interviews at the Central Community Organization (CCO). Months later, she performed the second step of translations on eight recorded audio interviews that were conducted by the first male Sinhalese research assistant at the Southern Rehabilitation Center (SRC). After establishing my fifth CBR field site, the Eastern Community Based Organization (ECBO), I reached out to a friend of a friend via email who connected me with my final research assistant. She was very experienced in conducting qualitative research, and her professional and interpersonal skills were a great asset during my fieldwork in the eastern region.

The two women interpreters I hired for the last sets of interviews appeared to make the women feel more comfortable speaking with me in confidence. This group of interviews, from CCO and ECBO, were much longer and contained more details about the women’s lives and experiences. Two of four interpreters I hired had experience conducting qualitative interviews in the past. The last interpreter worked on the final set of 10 interviews with women associated with ECBO. She had significant experience facilitating qualitative social science research with marginalized groups, and the data reflects that. It is also possible the lower depth of information shared by the interviewees in the first half of my project was a result of my lack of experience in
the culture and context. It is possible as I became more experienced and confident working with interpreters during the interviews, answers became more detailed and relevant to the research.

Identifying Field Sites

CBR field sites were chosen for both observation and recruitment. This choice is important because PWD are beneficiaries of services run by CBR programs, but are often excluded on multiple levels from meaningful participation in the rehabilitation process. Several programs were identified throughout fieldwork. Five, from four distinct geographic areas of Sri Lanka, served adult WWD. Each CBR program operated as a physical site for observations and recruitment and/or assisted in identifying women with disabilities in the community.

In addition to interviews with disabled women, six people in positions of leadership at CBR sites were also interviewed. Of note, one of the leaders, Nayana, was also herself disabled, and one other leader mentioned experiencing disability in the past. As noted above, once granted access to a CBR site, women were either approached in person at the sites, or identified as potential participants by leaders within the programs. When asked, Ramesh, a leader at ECBO, said he identified women for me to speak with based on their diverse set of experiences. He noted, for example, they came from a variety of economic and livelihood backgrounds, had varying marital statuses, and experienced different levels of exposure to the war. It is suspected some leaders identified women with a similar intent of diversity, while others may have located women who were “successful” recipients of their services (i.e., those progressing in paying back loans or utilizing skills trained through a CBR program).
Data Collection

Participant Observation at Sites

Site 1. The Northern Rehabilitation Center

The story of how I identified the Northern Rehabilitation Center (NRC) is detailed in Chapter 1. Gaining access and permissions to conduct research presented some logistical challenges. Basing my research in a Tamil speaking area meant consent forms had to be retranslated and reapproved by my university’s Institutional Review Board (IRB). Additionally, I had to locate, hire, and train an interpreter to conduct the interviews with me. I found housing close to the offices of NRC, living with a family for two months in a furnished house on their gated property. My landlady was friendly, and although her daughters were busy with school they provided me with potential contacts for local interpreters. After a few days, I hired a friend of theirs, a medical student in his twenties. He was very organized and direct. In addition to interpreting during the interviews, he accompanied me for observations at the NRC offices. He was helpful with understanding cultural norms and setting up logistics related to the interviews. We worked together for approximately two weeks at NRC. Only locating three women to speak with, he rightly insisted we look for an additional CBR organization to work with.

Although NRC told me they had community-based programing that involved a field officer (FO), I did not observe any non-center-based program activities after six weeks of intermittent observations (a few hours a day, for two to three days per week). I tried on multiple occasions to set up a time to go out in the community with the FO; however, he continuously cancelled. The lack of support for field-based work raises questions related to the impact of CBR programs in the lives of PWD. Additionally, it was very difficult to recruit women for interviews at this site. At one point my main contact asked if I could just speak to men since many more
men than women received their services. Often, the most talkative clients at NRC were teenage boys who wanted to practice their English while waiting for their appointment. In just under six weeks of working with the center, I recruited only four women to interview. I asked a leader at NRC if her program had hosted this type of research before and she said, “no, not like you. They don’t ask so many questions they just take numbers down.”

There was a sign posted on the wall at the center that read: “Let the able live more simply so the disabled may simply live.” While my main contact at the center was very supportive and interested in my research, the director of the program asked us, the interpreter and myself, to stay on the porch located outside of the primary offices. I was told our presence in the office was too distracting to the staff. A brief description of NRC is provided in Chapter 4. All four women contacted through NRC chose to conduct interviews at their homes. These were a mother/daughter pair located in a more urban area, and two other women in very rural areas.

Site 2. The Northern Vocational Community Center

As mentioned, the Northern Vocational Community Center (NVCC) was identified by the first interpreter I hired. He made the connection through university contacts. After a brief introduction to the organization’s leader Arunadhan, and an explanation of my research intent and protocol, we were welcomed to observe at the site. All six women contacted through NVCC chose to conduct interviews at the center where they lived and worked. The center was relatively accessible to town proper by vehicle, although it was more remote than the NRC. During the course of observations and interviews, I was invited by Arunadhan to attend a local government meeting organized in order to help promote the concerns of PWD in the area. The room of 60 plus people was mostly occupied by men, who were also the most outspoken when given the opportunity to voice their concerns.
The dominant issue expressed at the meeting concerned overall non-compliance with existing laws and regulations, specifically the “Disabled Persons (Accessibility) Regulations, No. 1 of 2006.” This is also the central legislation cited in a recent Supreme Court decision detailed in Chapter 1 (Ministry of Health & Directorate for Youth, Elderly and Persons with Disabilities, 2013; Perera v. Minister of Social Services and Social Welfare and the Chairman of the National Council for Persons with Disabilities, 2019). More information about NVCC’s program is included in Chapter 3. Prior to working with NVCC, Arunadhan was involved with other CBR programs. He said those programs were low-impact due to their lack of job training for PWD in the area. Without job training, PWD were most likely not going to escape poverty. When asked about his organizations focus on WWD, Arunadhan replied:

…women are more disabled, but they are the silent majority living at home. They are not at the road. Men are seen, obvious, but women are not. So, we gave the men tricycles to move about and all that. So, they were on the road. But women didn’t take the tricycle and go. They were very passive. So, they were at home so they were not prepared to exhibit. The men, they exhibit their disability and try to make some money. But women want to hide their disability. They don’t want to exhibit their disability. So, then I thought the best thing is to train them in sewing.

Site 3. The Southern Rehabilitation Center

The office of the Southern Rehabilitation Center (SRC), like the Northern Rehabilitation Center (NRC) and Eastern Community-based Organization (ECBO), was prominently located within the community in a central and well-trafficked location. Upon arriving to SRC, I was introduced to two leaders, Vimala and Dinesh. Staff and leadership at SRC were very supportive and engaged in fostering my research project. We were able to join multiple FOs in the community to learn more about what services they provide and the populations they work with. There was a bit of confusion at first about my research intent as they thought I wanted to interview “women with children with disabilities” instead of “women with disabilities.”
Nonetheless, the miscommunication was quickly resolved and they identified multiple women across the region for in-depth interviews. All 15 women contacted through SRC agreed to participate. They chose to conduct interviews at their homes and on their porches, geographically spanning three broad districts. All but one woman lived in a very rural location. Additional details about SRC are included in Chapter 5.

**Site 4. The Central Community Organization**

Finding the Central Community Organization (CCO), similar to locating the NRC, was a coincidence. I was eating at a restaurant near my house on the outskirts of Colombo and the director and founder of the CCO, Nayana, was at the table next to me. The restaurant owner was serving both of our tables. She had previously inquired about my research focus and my reason for living in Sri Lanka. She also, apparently, had known Nayana for many years and introduced the two of us. After briefly discussing my research project and the focus of my dissertation, Nayana agreed to set up another meeting in order to review the research protocol. CCO’s offices, and all of the women recruited for interviews, were in very rural locations. The women served by the organization lived across vast areas of the central region. Three out of eleven women contacted through CCO were interviewed at the rural residential program where they lived and worked with women with mental illness and intellectual disabilities (MI/ID). More details related to my experiences with CCO are included in Chapter 4, and data related to many of the experiences of women who lived at CCO are highlighted in Chapter 5.

**Site 5. The Eastern Community-based Organization**

The Eastern Community-based Organization (ECBO), the last organization to participate in this research, was identified after I moved to the eastern region of the country to live with a friend in my grant cohort. He lived in the community for over a year and told me of an
organization working with PWD in the area. Ramesh, a leader at ECBO, was supportive of my research. I quickly learned ECBO did not conduct CBR center-based services and instead acted as a mediator between PWD and the greater community. I was invited to attend a large disability awareness program and learned of their work in the community through that event; however, I did not observe any other activities or services they provided due to their limited number of staff. Additional information about my experiences with ECBO is included in the Chapter 5. All but one of the women affiliated with ECBO chose to conduct interviews at their homes. The women from ECBO lived across multiple districts within the eastern region.

**Participant Observation**

Traveling anywhere as an able-bodied person on public transportation was physically precarious. The doors often remained open on busses and created an open vacuum of air. While pleasant to the riders during constant overcrowding, it also felt at times that it would only take one sharp turn for people to fall down the stairs and out the door. At rush hour, passengers in the aisle were expected to plant their feet firmly and hold on to overhead railings or seat backs, if possible. The overhead railing was very high, making it difficult for most to grasp, and only extended so far toward the entrance/exit of the bus. One’s quality of balance at the front of the bus was completely dependent on grabbing onto other passengers or leaning against the waist-high protective railings that guarded the center engine area and the driver. Those three-foot high protective railings at the front of the bus, and the standing spot on the wall directly opposite the door, were prime spots for balancing but were difficult to secure on a busy day. On many hot days, young men traveling shorter distances would stand on one of the stairs at the entrance of the bus and hold onto a railing while their hair blew in the wind. During busy hours, people would have to disembark to allow passengers to exit the bus only to have to crowd back in again
before the bus began moving. Riding the train was not much different. On one journey a friend and I stood for over two hours before passengers disembarked and gave us their seats.

Often traveling after dark on a bus meant I was one of a few women among a bus full of men. I never felt uncomfortable; however, I realized by the reactions of passengers that my presence there, either as a westerner, a woman, or both, was out of the ordinary. Even in busy cities, opportunities to take public transportation thinned out considerably around dinnertime. Very few bus lines continued operating after dark. With a smart phone and generous grant income, in cities I had the option to use a web application to request an auto (a three-wheeled motorcycle with a rear cab) for transportation, My freedom of movement is reflected by the sample of women I was able to interview from multiple rural areas of the country. The majority, all but nine, chose to have interviews at their homes, often in very remote locations. From my descriptions, you may gather public transportation is not built with accessibility in mind.

**In-depth Interviews**

During each initial meeting, with the help of an interpreter, I shared written and verbal information about the goals of my research. At our first introduction, those agreeing to participate set up a return date, time, and location for the interview to take place based on their preferences. We told each woman they could have the interview wherever was most comfortable and convenient for them. All of the interviews were collected using a digital voice recorder. We asked sets of questions about daily routine, sources of family support, and degrees of community participation. To begin, the interview questions related to the women’s daily routine. A research assistant informed me that asking about breakfast was important cultural information to aid in establishing rapport. Often, toward the end of the interview the topics became more diverse and personal relating to the women’s experiences. As the interviews progressed, many appeared
more open to sharing information about their personal lives. This helped the conversation flow more freely. On average, each interview lasted approximately one hour; however, some took as few as 22 minutes, while others lasted over two hours. All interviewees gave informed consent prior to data collection and received a gift of approximately Rs.500 LKR. None of the women requested to withdraw or discontinue the interview.

All 46 interviewees were over the age of 18, spoke Tamil or Sinhala, and were recruited for one in-depth semi-structured interview. Half of the six leaders interviewed were women, and all were Sri Lankan. Five of six leadership interviews were conducted in English. The age of the leaders ranged between 30 to 80 years old, with the average around 60 years old. Aspects of the field site interview information are detailed in Table 1.

The average age of WWD who participated in interviews was 42 years old (range: 23-66 years). The interview sets began in the northern region with 10 women. Four were interviewed from NRC and three are quoted in the current research (Geetha, Tharany, and Sharona). Six women were interviewed at NVCC and four are quoted here (Ajanthani, Chithra, Neesha, and Jaana). Fifteen women were interviewed from the southern region and eight are quoted here (Chamari, Lakmini, Gayesha, Harshani, Shamini, Roshani, Thilini, and Kanthi). Eleven women were interviewed from the central region and 10 are quoted (Nayana, Maheshi, Bimali, Rani, Lalitha, Kumari, Hiruni, Asoka, Amanthi, and Jayanthi). Ten women were interviewed from the eastern region and all 10 are quoted here (Vaishnavi, Priya, Praveena, Ramya, Yalini, Pushpa, Tabitha, Thivya, Gayathri, and Reshika). For detailed information about the demographics of the women, see Appendix C. As discussed, prior to 2015 war-affected northern and eastern regions of Sri Lanka were mostly off-limits to assessment and inquiry. While historic geographic and
ethnolinguistic divides often result in research with Sri Lankan participants from similar ethnic backgrounds, the present study accessed previously understudied areas.

Twenty-six women spoke Sinhala and 20 spoke Tamil. The representation of Tamil women in this study is a product of enthusiasm from Tamil CBR leadership in allowing this research as well as a conscious effort on my part to document experiences of different ethnic and geographic identities in relation to gender and disability. Nearly all of the women, 44, had physical impairments. One was born hard of hearing and another had a vision impairment. The majority of women had no additional illnesses or health conditions; however, five had comorbid illnesses that required ongoing medical care. Half acquired their disability after age 13, and 22 prior to age 13. Twelve were born with disabilities, and at least six (13%) acquired disabilities due to war. Eighteen women (39%) reported they were never married; sixteen (35%) were currently married; five (11%) were abandoned by their husbands with children; two (4%) left their husbands; and five (11%) were widowed, three of whom lost their husbands due to war (See Appendix C for a detailed description of the women quoted).

The living arrangements of the women were varied, many indicated they supported themselves and other family members in their household (24%). The second most common living arrangement was dormitory-style housing for WWDs, and single women living in a family member’s house (each making up 20% of the sample, respectively). Twenty-five of the women interviewed (54%) were mothers. Eleven, 44% of the women with children, raised their children past the age of 18, while 14 (56%) still cared for school-age children. Ten, 40% of the women with children, raised their children into adulthood as single parents; and six (24%) were currently raising young children without a partner. Eight women (17%) were married and living with their husband (and sometimes children), and five (11%) were married and living in a home with
parents or adult children present. Two single women lived alone in a separate house, and two married women cared for both an aging parent as well as children in their home.

**Data Analysis**

Interviews were completed and translated into English. The de-identified transcripts were uploaded to Dedoose, a qualitative analysis software. Each interview was coded line-by-line. Coding is a transitional process between deciphering, or decoding, core meanings from a passage of data and then encoding, or labeling, that passage with a code or unit of analysis (Saldaña, 2009). Preliminary stages of coding consisted of reading transcripts and creating a code, a word or set of words, that identified the location and types of information spoken by the participants (Charmaz, 2006; Saldaña, 2009). Codes were developed based on interview text and reflected both the data related to contextual interactions between speakers in the interview as well as specific information shared. This process of analysis was inductive, guided by themes and codes that developed out of the data instead of looking for a predetermined set of codes or themes.

Initially codes were created and applied liberally to ensure detailed and ample amounts of data. The second phase of focused coding consisted of comparing, collapsing, and categorizing codes with greater precision (Charmaz, 2006). Codes emerged through this process and developed as I became more familiar with the data (Charmaz, 2006). They formed major conceptual categories through iterative analysis (Saldaña, 2009). For example, passages identified by similar codes were reviewed and collapsed (e.g., “men leaving women and children” and “fear of abandonment”). The emergent process of pattern-finding and meaning-making within the data led to the final stage of thematic analysis: identifying, layering, and grouping codes into overarching themes that serve as the foundation for continued inductive analysis (Charmaz, 2006; Saldaña, 2009). Observations across Sri Lanka, and within the CBR
sites, contextualize these themes and highlight areas of congruence and divergence related to the embodied experiences of being a woman receiving services from a particular CBR program.

**Reflexivity**

As an outsider crossing major geographic, ethnic, social, and class barriers, participant observation also served as a personal experiential process where “social reality is at least in part a product of an investigator’s efforts to apprehend and describe it” (Emerson, 2001, p. 20). Data collection in a post-war country with a long history of colonization in the global South required I examine my positionality as a researcher and information gatherer. As discussed, I spent 13 consecutive months living in Sri Lanka. While my extended time there provided many ordinary day-to-day observations, I am also acutely aware my presence, often as the only apparent outsider based on my skin and dress, occasioned particular responses from those I was there to observe. People often asked questions about what it was like in the United States, and if I liked their food. Other times, I was keenly aware of my financial independence and able-bodiedness in negotiating public places. Coming from the southern United States, a place with limited public transportation, I enjoy taking public transportation when available. In cities, this meant navigating buses that often fit three people standing sandwiched in the aisle, between already taken seats. Issues with overcrowding, unreliability, and inaccessibility with the most affordable method of transportation is a theme evident throughout this research.

As an American with a motorcycle and car license, I used my social and economic privilege, and my ability to wait five hours, to get a Sri Lankan driver’s license. I also had the financial means to temporarily hire a motorcycle or vehicle to transport myself and the interpreters to very rural homes where many of the women lived. A few of the homes were not accessible by car due to narrow and muddy roads that led to their area. Many interviewees
expressed interest in getting a license but lamented the required medical exam excluded them, even though they were confident they could safely operate a motor scooter.

Gender-based violence is an increasingly discussed topic in Sri Lanka (Fonseka et al., 2015). During an informational safety meeting for women in my grant cohort, we were told to consider traveling on crowded public buses and trains while equipped with a safety pin in order to discreetly deter men from getting too close. The idea was to open the metal pin and place it near your body in the event a man “bumped” into you multiple times. We were later reassured during the same session that white or foreign appearing women may need this form of self-defense less as we are believed to have powerful allies, and others might more readily come to our aid. My experiences while traveling all over the country reflect this sentiment and while one man on a Colombo bus was suggestively physically close to me, I never felt compelled to defend myself or enlist the help of someone nearby. My nationality and financial status afforded me the freedom of movement that many women in the country did not have. Given my positionality, I am unsure whether the women I spoke with edited information they provided about their lives based on my social status, nevertheless, I built a rapport with many of them and our genuine conversations are what this dissertation is built upon.

Navigating Fieldwork Limitations

Ethnographic methodologies serve to navigate complex lived experiences of individuals, and create an in-depth understanding of how customs and beliefs may be present in particular locations (Loveland, 1999). While methods detailed in this chapter provide ample amounts of context, factors involving reflexivity are always present. Studying phenomena mostly foreign to my lifestyle and experiences risk errors of attribution (Becker, 1996). When possible, I tried to address these limitations through the cultivation of knowledge from research assistants, local
experts, service recipients, and counterparts in the field. They helped me learn about and adhere
to prominent Sri Lankan cultural norms and expectations. For example, when research assistants
told me to always accept the tea if offered, or to bring a small amount of food to share when
visiting someone’s home.

Another limitation addressed early on during fieldwork was the inclusion of Sinhala
women only. It was through informal consultation with disability advocates in Colombo that I
learned of the importance of representing Tamil women’s experiences of disability in my
research. The war ended, but the geographic regions impacted most by the conflict were off
limits for many years to outside assessment and their experiences of disablement under-
represented in the research. The use of research assistants’ local knowledge was especially
important when conducting research in war-affected areas. Often, the mention of a specific year
occasioned a separate conversation outside of the interview that conveyed common knowledge
related to historical information about the women’s geographic locations and traumatic events
that occurred during the long civil war. Research assistants’ knowledge greatly improved data
collection and carried this work forward.

I acknowledge the “field” is produced both through my inclusion of some objects of
study and my exclusion of others (Emerson, 2001). Reasons for these inclusions and exclusions
are political and should be accounted for as much as possible (Mani, 1990). Acknowledgement
of ways social politics shaped the results of this study are discussed in brief below. Interactions
and data were ultimately produced through my actions and presence.

Conducting social research without a working knowledge of the language of those being
studied meant relying heavily on interpretations and translations. My lack of language
proficiency presented important ethical and empirical challenges. This is especially true
considering the breadth of a critical phenomenological approach, i.e., one grounded in the experiences of others while critiquing social systems they operate within. Working with mostly interpreted English precluded opportunities for linguistic analysis in terms of form, meaning, and context. Multiple South Asian scholars have asked me how interviewees spoke, inquiring about the specific words women and leaders chose to use to convey the concept of “disability.” This is an important question that may be addressable in future studies, as audio data was collected in Tamil and Sinhala. Working with interpreters and translators arguably diluted the conveyance of individual expressions and experiences, as the interpreters themselves are bound by their own language capacities. These bounds are likely reflected in the English transcripts of the interviews; however, I am confident the messages and meanings shared were accurately conveyed, albeit without as much linguistic nuance as a native speaker analyst would be able to engage.

Bernard (2006) describes a “third-party present effect” that may happen when others are in the room during an interview (p. 242). More often than not, at least one family member was present during all or some portions of the interview. Negotiating this proved challenging during fieldwork, especially in the beginning when I was not aware of the necessity to ask them to leave before starting the interview. When family members were present at the initial introductions we would ask for privacy, only to be re-joined by the family member soon after the conversation started. Sometimes the family member would even answer questions on behalf of the women.

Family presence sometimes appeared to impact the women’s answers. This adjustment was most apparent when the family member would leave for a while and the women appeared more relaxed in sharing about their personal experiences living with disability in the household. Requesting privacy became a more forceful part of the introductions, and requesting the family
leave the room during the interview became more socially appropriate, albeit still frowned upon, after hiring female interpreters half way through data collection. I also made my expectations of privacy clear when training the interpreters. In later interviews, we clearly stated expectations in the beginning of the interview and followed up during the conversation if a family member attempted to join. Assuring privacy during the interviews became more effective after an interpreter informed family we could speak with them after the interview.

**On Who is Visible and Who is Invisible**

With the exception of Sinhala/Tamil interpreters, none of the women included in this study required personal assistance to communicate during the interview. One woman identified as deaf, although she communicated via a Sinhala interpreter. While some women were randomly recruited based on their presence at the CBR program, many more were identified as possible participants by CBR program leadership. Women who were involved in their CBR programs and communities may have been more readily identified by the CBR programs to potentially participate in the interviews. For instance, when asked, one woman recruited from ECBO said she has been interviewed in a similar manner over 10 times, “because I am an active participant.” Women critical of the program, or those known to the program to have unsupportive families, may not have been referred to participate in this research.

The absence of Muslim women’s experiences must also be noted, especially as they are a population potentially more restricted in their physical mobility (Rajasingham-Senanayake, 2004). Although religious affiliation was not a direct question asked in the interviews, none of the women interviewed explicitly identified as Muslim. Nayana, the leader of CCO, said she has worked with all three ethnicities of women across the country. She said, as women, regardless of ethnicity, “we all have the same problems with disability.” She also noted, based on her
experience as a community leader, that Muslim women on the whole were a more reserved group who did not like to come out of their houses or “socialize with us.” I did not work or live in any predominately Muslim areas; however, in the beginning of my fieldwork, I attended a community-outreach event of a CBR organization that was not included in this research. The event was lauded as unique by the organizer for its ability to bring together Tamil, Sinhala, and Muslim mothers of children with disabilities to meet in a Buddhist temple. It is likely Muslim women’s experiences are qualitatively different from the Buddhist, Hindu, and Christian women’s experiences reflected in the data.

Experiences related to caste were not collected in this dissertation, though discussions of caste are still relevant in Sri Lanka and future work should consider experiences of caste at the intersection of disability. Additionally, none of the CBR programs who agreed to participate in this research provided services working in the Estate sector, a historically marginalized population and a geographic area marked by significant poverty. This sector is vastly understudied and future disability-related research in Sri Lanka should aim to address this.

Lastly, due to my university’s IRB restrictions, I was not allowed to include women with mental illness or intellectual disabilities (MI/ID). Their experiences and perspectives are notably absent in this research. Excerpts from women interviewed reference a correlation between gender, MI/ID, and abuse. Although no women interviewed currently experienced MI/ID, it is important to note these experiences are valuable and are too often excluded from social science research, including the present study. A home for women with MI/ID was the first to welcome my project; however, due to complications with processes of gaining their consent to participate in research, I was unable to interview the women.
Having grown up down the road from where the Tuskegee Syphilis Trials took place, I am keenly aware of the important purpose the IRB serves to ensure responsible contact with research subjects. Requirements to obtain consent from a legal guardian, as well as the person with MI/ID who may be included in research, are warranted in particular contexts; however, this requirement also creates additional barriers to inclusion and representation. These issues are important, especially as much-needed perspectives are absent in intervention research. Particular contexts and complexities of conducting international research focused on qualitative experiences of MI/ID are nuanced and should be prominently discussed in future research. CCO also served women with MI/ID, in addition to women in the community with physical disabilities. While I did not interview women with MI/ID at CCO, they were beneficiaries of CCO’s residential program.

Summary

We must actively consider ways in which to close the gap between those who write, those who read, and those who are written about. (Enslin, 1994, p. 552)

Chandra Talpade Mohanty (2003) argues the predominant model of feminist inquiry into experiences of women in the global South has often failed to organize women’s narratives into accounts of dynamic struggles and agency. Research presenting global South women as a homogenized group of powerless victims, without active agency, further colonizes indigenous knowledge and struggles (pp. 23-24). In order to advance political action and dismantle oppressive systems, investigations of global South women must shift away from monolithic representations and instead document a vast array of diverse realities, struggles, and opportunities.

Societal progress has been made regarding laws for community accessibility, inclusion, and participation of PWD. Still, significant socio-cultural barriers remain unaddressed. The
qualitative methodologies used in this dissertation are well positioned to illuminate the experiences of disabled Sri Lankan women. Their accounts are framed in the data as coming from agentic subjects; not objects or monoliths whose individual experiences are generalized, aggregated, or colonized (Mohanty, 2003).
CHAPTER 3. EDUCATION AND EMPLOYMENT: JUST GIVE US A CHANCE

Introduction

Education and employment are two primary areas within the CBR framework (WHO et al., 2010a, 2010d). These sectors are important when considering resources and pathways to thriving in the world. This chapter presents themes related to education and employment that emerged from the data.

Historically, formal education in Sri Lanka was uncommon. It was provisioned through religious institutions and open almost exclusively to male students (Jayawardena, 1986). A long history of colonization occasioned an educational system that funneled an English-speaking elite through English schools and privileged those already holding high society status. At the same time, the colonial system served to maintain the marginalization of the masses through sub-par education services within local-language schools (National Education Commission, 2017). Post-colonial education reforms increased the potential of Sri Lanka’s public education system, specifically through: free primary, secondary, and tertiary education; using Tamil and Sinhala mediums of instruction; and unifying into nation-wide system of schools (National Education Commission, 2017). Education levels are detailed in Table 2, and education levels of women quoted are noted in Appendix C.

Notwithstanding improvements within the educational system, “one of the most significant issues Sri Lanka faces is the uneven quality of and access to education, despite its commitment to the universal provision of education” (UN, 2018, p. 16). A lack of funding and an absence of a clear education policy are problematic and lead to inefficiency, strain, and uncertainty related to the constitution’s assurance of “the right to universal and equal access to education at all levels” (National Education Commission, 2017, p. ii). While there is no
comprehensive legislation concerning the education of PWD, Sri Lanka ratified the CRPD in early 2016. Ratification means they have agreed to be legally bound by the international treaty.

The Disability Organization Joint Front, an umbrella body of disability organizations, published a Universal Periodic Review report on Sri Lanka (2017) with the Office of the United Nations High Commissioner for Human Rights. The report stated “neither the minimum access nor basic equipment and instruments are available” for children with disabilities to receive an education from the state (p. 9). Liyanage (2017) wrote that inclusive-education policies exist, they are just not implemented because of stigma related to disability, and the state’s lack of “social and institutional cohesion and a multi-sectorial coordination body to implement interrelated and interdependent interventions from a holistic perspective” (p. 262). Research shows more efforts are needed to make education accessible for rural WWD who feel extremely marginalized across social, cultural, economic, and education sectors (Samararatne & Soldatic, 2015). Rurality, class, and gender also intersect in Winslow’s (2019) chapter on schools in Rural Sri Lanka. Using longitudinal data, she linked an increase in mobility and higher educational attainment to village boys’ “freedom to wander beyond the protective borders of the village itself” (p. 283).

Education is inseparably connected to employment, an area where PWD are often discriminated against. A government policy in 1988 instituted a 3% quota of positions to be filled by PWD in the public service sector. It was written in attempt to address discrimination, but is not in practice (Ministry of Public Administration, 1988; Disability Organizations Joint Front, 2017). A DCS (2014) survey showed 71.3% of respondents with “difficulties in functioning” were also “economically inactive” (p. 102), and a lower percent of WWD were “actively employed” compared to their male counterparts (16% vs. 45.9%) (pp. 103-104).
Unemployment rates range from 74-99%, depending on type of disability (Ministry of Social Welfare, 2003).

It is also important to understand ways employment is highly gendered. Indicators of gender parity in education have reportedly been achieved in Sri Lanka; however, “occupational segregation” is coupled with low levels of women’s labor force participation (35.9%), mirroring an overall trend in South Asia (UN, 2018, p. 15). The term occupational segregation describes the connection between women’s exclusion from academic courses in emerging fields such as technology and their over representation in sectors such as agriculture, self-employment, and unpaid family work (UN, 2018, p. 15). WWD are confronted with inadequate opportunities for economic independence. Padmani Mendis (2004) published data provided by the Department of Labour’s Wages Board that indicated 25% of women who reported being “currently employed” also identified as an “unpaid family worker” (Mendis, 2004, p. 8). Narrow avenues for women’s employability are further observed in vocational services that assume women should be relegated to “the private and gendered sphere of the home” (Hyndman & de Alwis, 2003, p. 215). This brief context underscores the interrelated nature of social and economic institutions in relation to gender and the profound effects they have on the lives of WWD.

In light of the current and historical background, findings detailed in this chapter do not view inequities in isolation. Instead, data reveal a systemic lack of formal education and experiential learning opportunities for WWD. The lack of potential pathways for livelihood realization is reinforced by patriarchal, capitalist, and ableist assumptions. Limited opportunities place further value (and also burden) on the role of families to expose their children with disabilities to society, as family and kinship networks provide crucial opportunities for new social and cultural experiences. Throughout the data, the life stages of the women are discussed
in order to provide important context related to their experiences of disability and CBR programs. The interviewee demographic information in Appendix C is included for this reason. Details of interactions with programs, government offices, community members, and kin-networks are also present throughout.

**Findings**

**Theme 1: The Important Role of Family: Give Us the Opportunity to Fail**

My mother carried me and went. For two years, she carried me to Grade 1 and Grade 2. After that, I got used to going on crutches. Since the school was walking distance, around 1 kilometer from home, I would go on crutches. [...] But before that, I would walk on all fours at home and go here and there. After I started going to school, and then using crutches, I would join my brother and sister to play or go to bathe in the public well. I was like everyone else. I had no bullying or special treatment. I had freedom like everyone else. (Nayana)

Nayana, the leader of CCO, was a renowned community activist. She used a wheelchair for mobility and modified her home, office, and the CCO program buildings for accessibility. She noted during our interview that was treated the same as everyone else by her mother and siblings growing up. She never felt sad, discouraged, or different. On the contrary, Nayana said she was different from most women because she is, and always has been, very active. She was "always fighting back" against discrimination. Nayana touched on what many WWD also noted as children in her description of being treated like everyone else growing up, that they wished to be given the same opportunities as their peers. Often, their discussions of disparate treatment centered on accessing education. CBR guidelines include facilitating inclusive education at all levels as a foundational programmatic goal, yet in reality none of the women noted education access as a benefit of their involvement with CBR programs. Education services for adult WWD were not present within the interviews, or at any of the five CBR programs observed, and no one spoke directly of government programs or assistance in relation to their formal education.
Inaccessibility of the education system was a common theme throughout the interviews, as was the powerful role of family members in mediating barriers and making the women’s lives as close to their peers as possible. Getting to school was the most salient barrier to education. Often, their mothers were tasked with physically carrying them when the women were very young. Some noted they stopped attending because the distance was too far for them to travel on their own, or when they grew too large for their mother to carry. Tharany, a college student in her early thirties with polio, was carried to school by her father who worked as a fisherman at night. He accompanied her to school every day, helping her up the stairs and from classroom to classroom. She and her mother Geetha lived in a relatively urban area, unlike many of the other women who lived in very rural locations. The impact of rurality on education was noted by women from every region.

Kumari, in her late forties, lived and worked at the CCO led by Nayana. CCO residentially served women with MI/ID, and also provided small loans and various trainings for women with physical disabilities in the surrounding community. CCO is detailed in-depth in Chapter 4. I was able to develop the most rapport with Kumari because I lived for a month in the same building as the residential program she oversaw. She invited me to watch television with her and a group of women at the center a few nights each week. Kumari would also sometimes sit with me on the veranda once the women had gone to bed for the night. One night, there was a loud commotion and I went outside to see what was happening. With excited mannerisms, Kumari informed me that the neighbors were shooting fireworks to ward of an elephant that was spotted nearby. I said I thought elephants were nice, and she exclaimed that no, they are very, very, dangerous. Thankfully, nothing happened and an elephant sighting only occurred once during my time in the very rural area of CCO.
Kumari grew up in a rural location and shared that she was scared to walk as a young child. Her experience with polio impacted her gait and she was carried to school until age ten. After a period of time, her parents stopped carrying her so she began to cry every day until they agreed to take her back. She eventually found the courage to walk to school. When I met her she walked at a regular pace although with each step she bent one side of her body down, seemingly to pick up and readjust one of her legs for proper balance. Her face appeared pained, with an expression of concern at times while she was walking, but she told me walking did not hurt her at all. In detailing her education struggles, Kumari felt “rich PWD did not have problems.” She equated village schools with poverty and poor education.

Ramya, a widow in her early forties recruited from Eastern Community Based Organization (ECBO), also explicitly identified the intersection of geography and class relative to rural education opportunities available to WWD. She was the only woman from that program to be interviewed at the center because she was already in town for her son’s tuition classes. “Tuition” are private special lessons provided by teachers outside of the classroom. Afterschool tuition supplements teacher’s low government pay, and an acquaintance even likened the cutthroat nature of teacher’s reliance on the supplemental income offered through tuition to the mafia. “The more money the parents earn, the more tuition the child takes” (Foondun, 2002, p. 489). Ramya’s story is detailed more in Chapter 5, including how she coped with the trauma of being injured and losing her husband in the war. She struggled financially while raising her son as a single parent and supporting her father:

If the parents are wealthy, they push their children with disabilities to let them study, to promote them or encourage them to study, and after their education, they are able to get a job. But these rural area people, no. They don’t have those opportunities.*
Many women referenced class status as a major alleviating factor that addressed barriers related to disability. As mentioned, expensive private tuition classes are necessary in order for students to succeed within a nationally competitive placement system. Ramya’s quote underscores the commonly expressed theme that families must push their children to learn and grow within an inequitable education system, one where the rich are perceived as successful regardless of disability status. Those like Ramya, with children of their own, often re-directed our conversation to discuss their struggles as WWD to educate their children.

Poverty and family status are important factors when considering a family’s capacity to support the education of their children. The vast majority of women cited a lack of finances as a major barrier to finishing school. In rural areas, labor-intensive low-wage agricultural work is often available but reliant on seasonal yields. Women in this study connected experiences of growing up in poverty to their parents’ work as day laborers, although none came from the low-wage tea and agricultural plantations classified as the Estate sector, an area where class, ethnicity, rurality, and exploitation intersect (Jegathesan, 2019).

Jayanthi, in the central region, was successful in managing an inherited agricultural livelihood. She was proud of her teenage son who recently performed well on qualifying academic tests. In her fifties, she told us of her own schooling while referencing both poverty and birth order as factors in discontinuing her education: “Because of our financial issues, because of our poverty, we couldn’t afford to buy books. Because I’m the eldest of the family I was the weakest. I couldn’t study well. All my other siblings studied well.”

Beliefs related to the labor of women in families, and the impact of birth order relative to caregiving roles of parents and siblings were often indirectly noted. These expectations highlight a clear example where gender, disability, and poverty intersect. Some women held additional
household and family responsibilities based on their status as an “akka” or an older sister. Differences in expectations were sometimes in reference to gendered provision of care to younger siblings, or, when the presence of siblings prompted parents to redirect resources away from the WWD. Tharany, from NRC, was in college and received extensive support from her father to physically attend school. She may have benefited from her birth order as the youngest in a large family in the form of more opportunities to receive parental support.

Asoka, in her late forties, was contacted through CCO. She also mentioned barriers related to poverty, birth order, rurality, and fear. Asoka had struggled to support her son’s education while running a small road-side stand. Table 2 contains information related to the educational structure. Asoka discussed why she stopped school at Grade 11:

My hearing is poor and my school had only up to O-Levels I had no way to go to another school. I can’t go on the bus, my hearing is poor, and I didn’t understand much. […] My mother was afraid that something will happen to me. […] Afraid to go on the road, my mother has never sent me alone to the road. I was accompanied and dropped to school […] We are poor and it was a long distance to travel to school. Unlike now, those days there weren’t schools nearby. Because we were poor money was scarce. For the fare it would take two to three buses for travel and someone would have to come along with me. […] There was financial difficulty and my parents had to work. If they could have picked me once after their work yes, but not when I go to school, they have to wait until it finishes. […] I have two younger sisters and a younger brother so can’t leave them and go. My mother couldn’t take me to school and wait until I finish, while leaving them behind, because she had her house work like cooking, preparing meals for us and had to be home when we got back from school.

Asoka’s quote provides context for issues that arise when there is a lack of infrastructure for working families with young children. Fewer schools in the country offer Advanced Level (A-L; A-Level) courses, compared to Ordinary Level (O-L; O-Level) courses requiring more travel and expense for rural students to study higher grades. Asoka was physically capable of riding the bus on her own, but her mother feared for her safety riding a public bus. It is not known, but it is arguably likely Asoka’s mother would have allowed her to continue schooling
had she had the option to ride a school bus or another safe and affordable method of transportation to school.

Geetha and Tharany were the only mother-daughter pair of WWDs interviewed about their experiences. Geetha and her family lived in a more urban area than many of the other women. She and her husband had four children, including Tharany, and also adopted two brothers who lost their parents during the war. Geetha’s interview was outside of the typical interview pattern. The majority of women, initially from NRC and NVCC, appeared more reserved. In contrast, Geetha very frankly discussed topics that concerned her. She exclaimed parents too often keep their children with disabilities inside, a practice discussed in greater detail in Chapter 5. Geetha shared how they always parented their daughter Tharany the same as her five non-disabled siblings. Tharany contracted polio when she was a toddler and was the highest educated woman within the interview sample of 46. Now in her early thirties, she was a few courses away from completing university. When asked if society treats WWD differently, Geetha explained how they raised Tharany:

Other families, they never teach their child with a disability in order for them to grow into a good person. They raise them inside the house, without studies and no work. They won’t bring them outside of the house, they just keep them inside […] because most of the people here are fishermen, they earn less per day. That money is not enough to teach them for their studies. But we think our children’s education is important, although others don’t think like that. My husband and I give first priority our daughter, because she has a disability. We don’t want her to feel she has a disability though, so when my daughter was in Grade 5, we dropped our daughter to the school and returned to pick her up. And for university we bought a three-wheel motorbike for our daughter and sent it to the university and wait outside the university. Like that, we give the most priority to our daughter. We never give any reason to make her feel she is disabled.*

Geetha was the only mother we spoke with who also had a disability. She took her daughter Tharany as a toddler to the NRC and thirty years later received CBR services for her shoulder injury. She and her husband committed to educating and teaching Tharany she was like
everyone else. Geetha’s cultural knowledge and experiences contextualize social barriers related to disability. She viewed physical difference as socially mediated phenomena and her rejection of a pathological view of disability was transferred to her daughter. Disseminating this style of parenting was echoed as a major goal shared by WWD throughout their interviews when they shared they just wanted parents, and society, to just give them a chance.

Amanthi, in her early thirties, was contacted through CCO. As a child, she wished for the same opportunities growing up with a disability. At five years old, she saw other children in her village attending classes and asked her mom if she could also attend school. Her mother went to the school and spoke with the principal. Amanthi walked to school until she was in Grade 6. In Grade 7, her legs began to turn back and she was forced to use a large wooden wheelchair for mobility. She had a physical disability that affected mobility in her arms, legs, and midsection. When asked why she did not continue in school, Amanthi noted the wheelchair was too difficult to use and always made her late for class:

My friends, classmates, everyone would help me to get to school. I was usually late because of the wheelchair. So, when I was in Grade 10, I felt like it was enough now, because my friends were late to school because of me.*

Amanthi’s statements underscore the important role of family and friends. Although she stopped school due to inaccessibility, she happily talked of the unique freedom she enjoys as a WWD when visiting friends and family around her village. Amanthi’s story of discontinuing education due to the need for better assistive devices, physical assistance, and time accommodations were all echoed in other women’s accounts of educational barriers. Asoka, mentioned earlier, was held back from school because of poverty and her mother’s fear that traveling on public buses to attend A-Levels was too dangerous. However, when attending the primary school nearby, Asoka’s mother advocated on her behalf and informed the principal of
her needs. He then informed all of her teachers to “give her special attention” and to sit her in the front seat:

They all spoke to me kindly, and all lessons that were taught in the class were taught in a manner enabling me to understand and learn as well. [...] Usually I sit in the front. But one day we switched classrooms and that day I couldn’t sit in the front and I had to sit in the back. Even the Sir forgot about it and he was teaching. Then I started to cry, and he asked me why. Then he remembered that I can’t hear and taught me the lesson from the start. [...] Everybody loves me because I’m smart. Because I was the first in my class always.

This section noted the important role of family in promoting the early education and development of children with disabilities. Even with support, it is clear no amount of assistance from family and friends could resolve the barriers of the systematic inaccessibility of the education system. Even with unwavering family support, the data above highlight pervasive barriers to physically getting to school. For example, a lack of safe and affordable transportation usurped strong family support and prevented young girls with disabilities from advancing grades.

Poverty and rurality also factor as major barriers related to the affordability and accessibility of transportation. In addition to incredibly supportive parents, Tharany’s family lived in a more urban area, meaning the A-Level school and university were not very far from her home.

Additionally, with a father, four older brothers, and her husband, she had more access to society via male guardianship and assistance, a theme woven throughout this research. As mentioned above and throughout this dissertation, the practice of sheltering children with disabilities often overshadowed the experiences of those who felt pushed to excel by their families. The next section carries this discussion of physical inaccessibility forward and presents data centering commonly shared struggles of neglect and isolation.
Theme 2: Inaccessibility, Neglect, and Isolation

Many women felt supported by peers and teachers in school, yet this support did not mitigate structural barriers such as poverty, war, inaccessibility, rurality, and a lack of safe transportation to and from school—major barriers that prevented many from furthering their education. Almost all referenced or spoke of struggles they encountered in their studies. It is a challenge to really communicate the physical inaccessibility of Sri Lankan public transportation unless you have experienced it in person. My description of navigating public transportation is included in Chapter 2. Many women attended village primary schools that did not offer O-L or A-L courses, and they detailed issues that might have been alleviated if there were programs to ensure safe and affordable transportation for children to get to school.

Here, it is important to provide a picture of the kind of travel required to for some of the women to leave their homes and villages. To illustrate this, and the associated difficulties with transportation, I describe some of my observations visiting their homes. The paths to reach some homes were not traversable by car. Houses in more remote villages sometimes had miles of narrow dirt paths that could only fit an auto (a three-wheeled vehicle), or sometimes just a motorcycle. To access one home in a remote flood prone area, we had to get off the motorcycle and walk it across the path for a small treacherous stretch. Once past that area, we located her home at the top of a steep and narrow muddy hill. I was grateful we scheduled the interview on a day without any rain. A few women with significant physical impairments that impacted their gait lived at the very top, or the very bottom of steep and unpaved paths. During the interviews, they indicated they climb the path if needed, although getting to their homes while securing my own footing was precarious at times. Many traveled short distances by walking, while others required physical assistance and had to be transported by auto. Implications are wide spread
concerning the lack of accessible and affordable methods of transportation and cut across multiple areas of the women’s lives. These struggles are discussed more in Chapter 4. The following section examines neglect experienced in the classroom, after the women managed to overcome obstacles to get to school.

Neglect Inside Classrooms

One interviewee working at NVCC stopped schooling while taking O-Levels because it was too difficult to physically change classes and follow her academic schedule from class to class. She explained sitting for a long time in a chair made her knees hurt and carrying the required books was too difficult. When asked if her teachers were helpful, she replied, “Some were helpful. Now people accept the rights of people with disabilities but twenty years ago no one had mentioned it.” Another said carrying books for her courses also presented a challenge. Lakmini, in her thirties, lived with her mother and multiple siblings in her older brother’s house. Like almost all of the women, she also enjoyed going to school. She received a hand-powered tricycle from SRC to increase her mobility when she was 10 years old. Prior to that, she walked half a kilometer to school by balancing on her hands while friends carried her books. I asked if her teachers were helpful or could have helped her more, she replied very specifically:

The Department of Education did ask them to make me sit separately for the exam, but teachers didn’t. […] When teaching they didn’t help me. They didn’t help at all. They could have, it’s hard for me to write. Even for the desk I’m too short. They could have made me a special desk separately and placed it somewhere else and taught me separately and not with other students. When I’m among the students, they can see the blackboard but I cannot. Therefore, they could have made me a desk and kept me in the front row of the classroom and taught.

Lakmini desperately wished to continue in school but was not allowed to because of her test scores. Her quote evidences ways children with disabilities are often at a notable disadvantage within educational systems that fail to provide even basic accommodations for
learning and inclusion within the classroom. The barriers they describe often would have required very simple adjustments; however, the neglect of stakeholders such as teachers and administrators who refused to implement minor adjustments or advocate for slight changes had cascading effects. Her experience echoes others. Harshani, a young woman in her early thirties from SRC also felt teachers did not care about helping children with disabilities:

Teachers did not look into us that much, they should have tried to take us forward, they didn’t do so. They just ignored and neglected me, because of my leg. They helped others. They should have taken us forward, but they didn’t help us.

Roshani, a blind woman in her late forties was raising her teenage son with the help of her sister and brother-in-law. She stopped schooling at the age of eight and shared similar experiences of neglect by teachers. The only blind interviewee, her physical journey to and from school every day was very easy, but she stopped attending because of her teachers and peers:

I couldn’t write letters and the teachers did not help me, they didn’t treat me well, so I stayed back home. […] Because I was disabled, they did not pay much attention to me whereas they should have paid attention because I had a disability. So children who are not doing, or who cannot write letters or who are not performing well in the class, they didn’t care much about us. All they cared was about the children who could write and who performed well and all the others they sort of neglected. They carried forward the children who could do, but they were not motivated enough to help the children who were not performing as well as the other children. […] I used to walk to school, and since the school is very near going was not a problem at all. But after going to school and being neglected by the school children and teachers, because they didn’t pay much attention to me, that’s why I stayed back at home.*

Even at such a young age Roshani knew the education system was not built to support her. She grew up in the 1970s, around the time a 1973 education ordinance reinforced provisions from 1947 that called for the establishment of “educational facilities in exceptional cases” such as “for the education of blind, deaf, defective and epileptic children” (Education Ordinance, 1973, p. XIV/125). I am unaware of any disability-related research that includes the experiences of children or adults with disabilities who may have been impacted by this legislation. Jayanthi,
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grew up with a visible hand/arm impairment below her elbow. She also shared feelings of neglect in relation to attending primary and secondary school. She left school at O-L because she “couldn’t study well.” Like Roshani, Jayanthi was impacted by negative experiences while at school:

They taught me, that’s it. No more. They did not do anything special for me, just treated me like other students. […] Back then, they didn’t really care about disabled people, they just let us stay. Nowadays it’s different, now people at least care a little. Back then, no. […] My classmates would always blame me, mentioning about my hand and I was very rude, I would hit them, both boys and girls. The teacher has not stopped them. They were talking about my disability, and it’s there, so nobody really stopped anyone. They would call me a name, and I would get really shy when they called me that. Now I don’t care, even now they call me names like that, but not to my face. Now I don’t get angry because it’s there and I can’t stop them saying those things.*

Jayanthi’s comment, like many others, highlight the need for PWD to not only be included in classrooms, but also protected and supported to succeed. All children need opportunities in order to learn and grow in an environment that supports them and is free from bullying. Jayanthi’s quote is also striking because it displays her growth from a shy and bullied child, into a strong, confident, and happy woman involved in her community who supported her family through various successful livelihood projects.

Kumari was a primary contact at CCO. She was introduced earlier in this chapter and provided the longest and most in-depth interview at over two hours long. She spoke of her experiences in school and exposed multiple overlapping themes related to family support, inaccessibility, and neglect. Kumari attended a “good school” during Grade 1 but was forced by her parents to go back to the village school, a closer walk to their home by two kilometers. In Grade 3, her parents stopped carrying her to the village school so she cried daily for six months until they agreed to take her back. She felt the rural village teachers were not helpful and often left her behind. In Grades 6 and 7, even though she was more athletic than many of her peers and
wanted to participate in physical education class her teachers told her she could not participate because it might trouble the other students. She attended that village school until Grade 9 and was very excited when her exam results placed her back in the good school again. She spoke of the village school’s long-lasting impact on her personal development:

In village schools the education is not so good and there are a few teachers only. [...] The teachers in the village school didn’t help me much. I went to the other school first and then came to this village school. [...] I was attentive and would always complete whatever exercise the teacher gave and would show my book. But the teacher paid more attention to her daughter [...] So, I lost confidence and I was afraid since she would scold and also beat me and the others. Unlike now, those days, teachers hit us. Even for something small, not for doing anything wrong, but for standing up and wanting to read the lesson. [...] Most of the time nobody talked to me. I didn’t have this in Grade 1, in the other school where the teacher was okay [...] There, the teacher was fond of me and would take me to the front at times [...] Because I went to that school, I’m now capable to read and write at a good level. If I continued going to that school from Grade 1, then I might perhaps be in a better place today.

Kumari’s quote notes the long-term impact of years of subpar education. Unlike other women interviewed, she was able to compare her village school to a good school. Although many wished they had been helped more by teachers in school and “pushed” forward, others spoke of very supportive teachers and peers. Notions of being pushed forward and of parents allowing their children with disabilities to learn and grow are present throughout the interviews. Experiences with neglect and barriers to early education impacted women many years later.

Their mere presence in a classroom was a feat evidenced by their parent’s hard work. Yet, their attendance without meaningful instruction was not enough to earn eligible marks within such a competitive system. A lack of alternative opportunities available in order to continue through the required education levels and earn a diploma are evidenced by how women spoke of their struggles as adults without formal education papers. These issues are detailed later in the chapter. This section described how physical barriers, poverty, and ableism compounded to impact performance on very important exams that determine eligibility to continue education. The
findings presented above indicate many women felt neglected and not pushed enough by their families or teachers to reach their full potential while in school. They often attributed this neglect as a result of being viewed and judged by others as disabled.

**Confronting the Cycle**

“My Children Should Continue What I Missed.” Often, when discussing women’s past experiences with education the conversation would inevitably transition to the need for parents to bring their children with disabilities out of the home. Many women also redirected conversations about their own education toward their struggles as mothers to educate their children. The practice of keeping PWD inside their home was a common theme woven through all of the chapters and are detailed more in Chapter 5. At the end of the interview, I asked Maheshi if she wanted to share something that we had not discussed. She wanted help for her teenage daughter, “My time is finished. I am old now. If you can, try to help my daughter because she is very talented at sports and she has competed nationally but doesn’t have a trainer.”* The wish to help their school-aged children succeed was echoed by many women. One wanted to put her daughter into preschool, an expense she could not afford as a single mother in her rural community. Gayathri, a widow in the east, spoke of the need for WWD to have permanent jobs so they could educate their children:

In school, I studied well. I could study but I dropped it. Now, I only focus on teaching my kid very well. I don’t want to drop my kid’s education. He should continue what I missed in my life, but the NGO work is not permanent. This is the third organization I have worked for.*

Gayathri’s struggles to financially support her family through stable employment were expressed from her viewpoint as a mother who wanted a better life for her child. She stopped schooling at Grade 10, age 15, because of the war. She held various short-term contract positions working with local NGOs. These were good jobs while there was work, but they were not long-
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Asoka also mentioned struggling to afford her child’s education as a single mother with a disability while running a small shop. Her neighbor’s husband was helping pay for some of her son’s basic needs such as school materials, fees, and tuition classes. This was a common struggle, as WWD often spoke of their family’s past struggles to provide books for them during their school-age years. Today, tuition classes represent a significant issue and talking point. The need for tuition implicates an unequal playing field for children of working-class families in their parent’s pursuit to advance their education in a ranked system. Ramya, a widow and single mother interviewed at ECBO noted “so many” problems face WWD in Sri Lanka. She said transportation was a major challenge and then discussed her struggles to educate her son:

Private tuition classes are 10 kilometers away. That’s my biggest stress and responsibility. Sometimes I have problems taking him. In the early morning I have to wake up and prepare lunch and I have to get him ready for school and take him. I need to take him to tuitions, that’s a big responsibility. I’m able to prove myself in other areas but this is a big challenge for me and sometimes I, I, couldn’t do anything. I’m very slowed down. And I have to go, after cooking I need to go to work, then I need to complete the work and after the work, I need to bring him to the tuition classes then, at night, around seven, I need to go back home and again I need to prepare dinner. […] I am alone, my father is living with me, so he supports me to cutting fish, only fish (laughing).*

The cascading impact of lacking education papers and relegation to low-income jobs, all while struggling to support families as single parents are evident in this section. Tuition classes are no longer considered a supplemental luxury, but are instead necessary to earn a placement in a highly competitive and ranked national qualifying system. As Ramya noted, the private tuition system adds not only extra expenses but requires time and transportation after school hours. Her husband died during the war when her son was an infant, so she is required to fulfill both the role of earner and caretaker for her son and aging father. Her joke at the end of her quote indicates while she is confident in completing her work, she is resigned to her father’s role in the home.
Theme 3: Incomplete Studies and Economic Precarity

*I Don’t Have Papers, “I Am Resorted to What I’m Doing Now”*

Two women who attended private boarding schools both had reliable jobs, one with the government and one as a seamstress. They were two of only a handful of women who secured a dependable stream of income. Tabitha lost her leg in a train accident and was an orphan from a very young age. An instructor at her boarding school taught her to become a very talented seamstress. Priya, contacted through ECBO, was working for the government. Like Tabitha, she also grew up without a father. She connected his absence to growing up very poor and her family’s reliance on the charity of others. The importance of men’s roles and how they impact the mobility of women are discussed more in Chapter 5. Throughout this dissertation, the absence of male family members is striking. This impact is evidenced by women’s struggles to provide non-monetary labor within the home while tasked with the additional responsibility of earning money for their families. Many women attributed their financial challenges to a lack of education and limited employment prospects.

Multiple women and CBR program leaders identified self-employment as the most attainable method of income based on WWD’s social, educational, geographic, and gender status. Self-employment often took the form of running a small home-business selling items to neighbors. These stores were typically small and located on a covered porch where they sold general household items. Multiple homes in rural neighborhoods have these shops and sell the same items at a very small profit margin. Few customers, paired with plenty of neighborhood competition resulted in variable and sporadic income. Many women, especially from CCO, received small loans from the program to invest in home-based shops and were working to pay off those loans.
Some women dreamt of higher status wage-employment in the form of office work. At the same time, they lamented these types of income-stable jobs were only open to women with diplomas. Only two women out of the whole sample, both working in the government sector, were engaged in wage-employment, although one was on a monthly contract. While these two women enjoyed consistent paychecks, the vast majority of women struggled day-to-day. They noted barriers to completing their education were long lasting and impacted their options to find stable sources of income. Harshani from SRC exclaimed:

Why did I stop? I couldn’t go to school continuously and so I couldn’t get good results. They don’t look in to us people with disabilities that much; they just ignored and neglected us. They didn’t help me very much, so my results were not enough for me to do A-Levels.

Harshani’s quote touches on neglect experienced by many WWDs growing up as children with disabilities in the education system. Experiences with ableism directly impacted their future employment possibilities. Harshani’s words also highlight an awareness of her place in a society where she was prevented from learning due to inaccessible schools in her rural neighborhood. Experiences of neglect impacted her opportunity to continue her education. Many women enjoyed school when they could attend but were also resigned to stopping when they received poor exam results. Yalini, in her fifties, struggled to support her teenage daughter as a single parent. She was born with physical differences and had stopped schooling at the age of 15. Yalini participated in multiple community-based trainings over many decades. We contacted her through ECBO, and she spoke about her confidence in conjunction with a lack of opportunities to support her family:

I don’t have any big challenges or problems. I am confident in whatever I involve myself in. […] I can go anywhere and talk to anyone and I can participate. But I have one worry, I couldn’t continue my studies and I realize that if I studied, I could get a better job, but unfortunately, I couldn’t get it. I didn’t complete my studies so that is the only problem that I have.*
War, poverty, disability-related stigma, and inaccessibility are all reasons attributed to a lack of quality education the women received. The interviewees believed in their intellect and ability to succeed, yet also spoke of the long-lasting and wide-ranging impact not having a diploma had on their lives. Some passed all of their subject tests, only to be told there were not enough spots to advance in the over-burdened and under-resourced system. Acceptance into the higher levels of education is not only dependent on passing exams but also on attaining scores that place you within a top percentage of test takers in your test-year. The women’s strength and resolve in the face of multiple barriers was pronounced throughout my interviews and observations. Many courageously struggled against poverty, sexism, conflict, stigma, neglect, inaccessibility, loss, violence, and ableism over the course of their lives. Findings related to women’s leadership and an emerging disability movement are discussed in Chapter 5.

Dinesh, a leader at SRC, also lamented about the education testing system. He once dreamed of being a doctor while doing his A-L in the science stream, “I cleared the exams but I didn’t have enough marks to enter the government system. [...] then I just had to find some other way to go ahead.” So he worked in a CBR program that allowed for training opportunities and educational funding for him to earn an advanced degree outside of the country. His experience highlights the circular relationship between a need for professional training and expertise in multiple human service areas and the absence of adequate graduate-level training programs in the country. The impact of this issue is widespread and trickles down. He said, “for the younger generation to be educated, you need to have educated people in the country with qualifications who can train.” A limited number of professionals means less exposure to development within intervention fields, and fewer scientific and technological advances. Lived experiences connected to barriers related to a lack of education and technology are evident from this data,
especially in the area of health, rehabilitation, and prosthetics development. These themes are discussed more in-depth in Chapter 4.

When asked if training and work opportunities are different for men and women in Sri Lanka, Jayanthi said, “women have less opportunities, and I don’t see a lot of disabled women working, although in my case I didn’t have a good education, so maybe that is the reason.”* Her statement notes women’s lack of opportunities and are a direct reflection of a patriarchal and stratified system regarding gender and work. Women detailed another prevalent example of an imbalance of opportunity when they told me they are less likely to get a license compared to men with disabilities. They also discussed multiple instances of pervasive institutional discrimination related to disability and gender, noted in Chapters 4 and 5.

An unequal provision of economic resources is supported through social structures and cultural systems that give more opportunities to men. Women are expected to work in the home and ways WWD struggle against the socio-cultural norms denoting men as resource bearers are discussed more in Chapter 5. Both men and women are socialized into the current system and hold particular beliefs about gender roles. We met Sharona at NRC when she came in for a prosthesis fitting appointment. She was disabled by a shell blast during the war. In her late twenties and living with her husband and young son, she shared, “It's good if men receive more support, it would be wrong to wish they receive less. In many cases, ladies do household work and men work outside the house. Families depend on them so we must support the men.” Although during her interview she personally wished for employment opportunities to help support her family, her statement reflected an understanding of women’s positions in a current system that provides more economic opportunities to men.
Some women said if given the choice and the opportunity, they would like to work in an office setting or become teachers. More often, when presented with a similar question about their ideal job, they responded with a sentiment closer to what Chithra, a seamstress in her thirties at NVCC, shared, “this work is decided by our level of study, so I will do any work because I didn’t study. This work is okay.”* Chithra’s quote synthesizes profound connections evidenced throughout the data in this chapter between education experiences and later employment prospects, both impacted by ableism and sexism. Like many women, she resigned herself to the living she was able to secure. Although Chithra liked sewing, many women who had been trained to sew stopped or would stop in the near future due to physical limitations and personal preference. Ajanthani, in her thirties working at NVCC, said she would most like to be a teacher but could never work for the government without a degree. One day, she hoped to work from home as a private language tutor for children. Neesha, in her forties, worked at NVCC for many years. When asked about her dream job, she replied:

I studied things like Photoshop. Though I don’t have a diploma, I can do all that. They would want to see my results if I am to work in an office. Had I finished the Ordinary Level, and then Advanced Level, with those results one could find an office job whenever there’s a vacancy. Now that I haven’t studied them, I am limited to these jobs. When you compare us with the ones with exam results, there’s a disparity in the opportunities and jobs are hard to find. Thus, I am resorted to what I’m doing now.

In her statement, Neesha shared both her competence and confidence in her ability to complete office work but noted people like her, with low results, are limited without a diploma.

Sharona, quoted earlier, lost both of her arms in a shell blast during the war and discussed this issue more in-depth. She mentioned the lack of exposure for WWD was the biggest issue limiting her opportunities:

Most people think disabled people can’t do anything, can’t do any kind of work. Society can’t understand our problems. Here, they don’t give any opportunity for us to explore our talents. They don’t know about me, that I can do this kind of work. People and
organizations should expose our talent to the society and only then we will get more opportunities.

Sharona felt her rural location meant she received fewer opportunities of help from programs designed to assist PWD. She was one of the only disabled people in her village, and said a friend and WWD in a distant village had received multiple opportunities in her community to participate in talent exploration and development programs that Sharona also wished to attend.

**Mono-focus on Individual Trainings and Skills Development**

By far, the most prominent activities provided by CBR programs occurred in the livelihood sector. Many focused on technical skill development and home-based self-employment (WHO et al., 2010d). These skill development trainings were heavily focused on sewing, an issue critiqued in this section. Wage employment, the most stable form of income, was effectively absent. These livelihood programs, by design reflect a “persistence of patriarchal definitions of womanhood in the arena of wage labor” (Mohanty, 2003, p. 143) and illuminate neoliberal and exploitative capitalist devaluations of women’s work. As noted, a few women worked for CBR programs earning a small monthly stipend, and two worked for the government. Other than for a small sub-set of women, opportunities for wage labor were effectively absent. Another facet of livelihood development, financial services, were only present in the form of CBR programming as microloans for income-generating projects.

The myopic focus on individual trainings through CBR programs to do certain types of work did not mitigate the fact women were unable to make a living using these skills due to structural issues such as inaccessible transportation. CBR-provided trainings ranged from incense making, newspaper/paper rolling, sewing and tailoring, jewelry/keychain making, rope making, and greeting card, paper flower, and small statue making. Many spoke of being fluent in computer programs. Some had gained those skills from CBR trainings while others were self-
taught. CBR’s focus on technical skills development comes at the expense of addressing larger systematic problems that lay at the intersection of gender and disability. Vocational programs for PWD may provide unmarketable skills not on par with the current labor market (Disability Organizations Joint Front, 2017, p. 10). The failure of intervention frameworks, such as CBR, to improve women’s socioeconomic status uncovers a core issue involved with programs that ignore structural issues such as sexism and ableism.

**We Don’t Need More Trainings, They Need to Know About Us.** Sewing and tailoring were by far the most promoted types of skills-trainings provided by CBR programs in this research. Other trainings mentioned during interviews included: business management (1); cash management training (2); communicating with others (1); center-based computer training (1); gender balance training (1); leadership training (5); personality building (2); and tailoring (27). A few women attended numerous types of trainings, while others cited that travel or companion expenses, physical inaccessibility, or illness had prevented them from attending trainings.

Some shared the programs helped them to gain marketable skills. More commonly, the women identified a lack of exposure as a more pressing issue. For many, the need to educate their communities about their talents was more important than the prospect of attending additional trainings. When asked about the utility of CBR trainings, Sharona was one of many women who expressed she already possessed multiple skills and did not want additional trainings—just more opportunities to use and market her talents. Some spoke directly about disability-based discrimination in the area of employment, detailed more in Chapter 4.

Instead of attending to the rampant sexism, ableism, and discrimination in society CBR programs primarily focus on individual trainings and development. The issue remains that no amount of trainings targeted at WWD address larger systemic issues of ableism continuing to
OPPRESS them. Even with a college education, Tharany, who was mentioned earlier along with her mother Geetha, shared, “when searching for work some companies avoid me because of my disability. Society should accept disabled people and give us the same opportunities as others. Treat us same as others.”* Similarly, Kumari felt limited by her current work position:

You must educate people and show them our skills. [...] my skills are limited here, and they haven’t been identified. There has been no room or opportunity to develop or showcase my skills. [...] After I came here, then only I realized, why couldn’t we try harder and help the disabled by giving them an opportunity too?

Data in this section highlight the fact that no amount of trainings, skills, or talents individuals possess can counteract the ableism that prevents them from displaying those skills in society. Findings presented support the need for a paradigm shift in CBR policies and procedures and indicate a need to reconfigure who the intended targets of rehabilitation should be (i.e., families, employers, teachers, and communities). I will now describe one CBR program in order to illustrate these issues from an organizational level. These observations indicate some programs may be considered a metaphorical Band-Aid applied over a broken system where opportunities for the advancement of WWD are few and far between.

The Dominance of Sewing. The Northern Vocational Community Center (NVCC) led by Arunadhan was located in a residential area. The center was a kilometer or so from many shops and about four kilometers from town proper. I was confident in my interpreter’s ability to locate the NVCC office, but the surrounding area was so residential I felt as if I was walking into someone’s private home. There was a large gate with an open paved area leading up to the front door. The staff at the center welcomed us and we waited on a church bench just inside the front door. Informational posters and a formal picture of the founder hung on the wall across from us. The picture was inside a frame that appeared to have been hanging in that spot for many years. Sounds of machines buzzed intermittently and a woman to the right of us was perched at her
sewing machine while sitting on a large circular wooden platform not far off the ground. This was her work area and it was covered with a thin cushion and fabric with her sewing machine in the center. She worked using both her hands and feet to operate the machine and quickly manipulated the fabric she was working with.

After speaking with Arunadhan and meeting a few of the women NVCC agreed to host my research. We walked around the work area, the largest main room with desks and sewing machines all set up. We viewed the kitchen and a few small sleeping areas with cots. Some women training at the center slept on the floor due to a lack of sleeping space. Approximately 10 women stayed at the center and a few more intermittently came to use the sewing stations during the day. NVCC was designed to provide a few months of training and access to sewing machines for a group of women who were then expected to reintegrate back into their communities.

Arunadhan noted NVCC’s structure as beneficial for many reasons. First, he said if the women did not stay at the center, they may not have their basic needs met such as food and security. Second, he noted disabled women are the silent majority living at home. They do not go outside and display their disability, whereas men, “are seen, obvious, prepared to exhibit their disability and try to make some money.” Arunadhan’s first CBR project had failed. He received a grant to buy WWD sewing machines so they could work from home. He said his previous approach failed since, “no one would hire them to tailor because community members disliked the women’s homes, because their men were drunk, floors were dirty, they didn’t have tables, clothes would smell after being worked on, and there was no changing room.”

To address this, he began working with NVCC to provide machines, training, accessible work spaces, and facilities at a center where the women could satisfactorily interact with and fill sewing orders commissioned from community members. He noted the current training model is
more sustainable, and many women aspired to go back to their villages so they could live near their families and work. Other women working at the center previously tried to work in their villages only to find they could not get not enough orders. Arunadhan talked at length of NVCC’s future plans to develop a center to display and broker PWD-made materials so the women would not have to rely solely on commissions from local buyers.

As mentioned earlier, a large number of women participated in some form of sewing and tailoring programs using a sewing machine. This is in line with the self-employment focus many women felt relegated to because of their level of educational attainment. The almost exclusive focus on sewing as a means of livelihood for WWD is important to note. Many were coping with secondary ailments such as low vision that impacted the quality of their products. While multiple women noted they liked sewing as an activity, many more detailed difficulties they encountered with learning and performing tailoring as a technical skill. Some could not use the standard sewing machine because of low leg function or other physical complications. Overall, vision problems were the most cited reason for not being able to complete tailoring work. Asoka said she liked to sew but her eyesight was too poor. Amanthi also experienced poor vision in addition to headaches when looking down to complete sewing projects. Improved vision is one the few areas evident in the current research where an individual focus on rehabilitation is warranted in addition to community-wide interventions.

Prior to working with NVCC Arunadhan had worked as a public health professional. He discussed his first attempt at CBR working with an organization that provided assistive equipment for PWD:

I went to the village to find out what these people were doing with the artificial limb. Most of them were begging. They removed their limb and kept it on the wall. [...] they said, “What else can we do? We can’t do anything.” I said, “What is the purpose of
putting an artificial limb for you to get back to normalcy?” They said, “no one is giving jobs.

Arunadhan’s comments touch on the need for CBR to incorporate a model of holistic intervention, both at the individual and the societal level. His comment acknowledges discrimination and lack of jobs PWD must deal with, and at the same time notes the futility of programs providing one form of intervention while ignoring others. Arunadhan’s solution to the problem in his story was to train PWD to fulfill particular roles in society. For WWD this means a strong focus on training them to use sewing machines while providing room and board.

NVCC focused on women’s livelihood training and self-employment in the form of handicrafts and tailoring; however, a unique feature of the site was many of the women ate, slept, and worked within the center. Arunadhan told me the women paid a percentage of their earnings for room and board to “make them realize they are not getting everything free.” Their take home pay may be different, but their basic needs such as food, clothing, and shelter are met regardless of the amount they paid. Individual living costs may range from Rs.50 to Rs.2,000 a month for room and board, depending on the women’s skills-sets and earnings. When asked about the rationale behind a residential versus center-based CBR sewing program for WWD he replied, “basic needs are given, and security is there.” Arunadhan said he framed the program in terms of Marx’s theory of provision of basic needs, laughing that he is “now practicing a defunct political system of communism.” When asked how he identified women to train, he said he “takes only middle people and tries to develop them so they will look after themselves. Those other people, someone else has to look after. If I take that on, it is useless.”

Sewing and tailoring provided successful livelihoods for a few of the women interviewed. Jaana, working at NVCC in her late twenties, spoke about the importance of technical skills and employment in relation to boosting the self-esteem of WWD:
They have no confidence because other people see them and laugh. I can’t accept that because I work the same as other people. I did the work and I became good at it. In the future, other people will give me respect; automatically give respect to my talents.*

Neesha, quoted earlier, worked as a seamstress at NVCC for many years. She stopped school at the age of 15 because of the war. She was one of the oldest women working at the center. During her interview, she discussed how negative images of self-worth are perpetuated when community programs merely hand out food and items without empowering PWD in ways that will make them self-reliant through job training and skill development. An in-depth discussion of CBR in relation to neoliberal discourses and charity is included in Chapter 5. When asked what kind of change Neesha hoped to see in society, she replied:

There are so many like us, aren’t there? The ones who think that they don’t know anything, they can’t do anything right. It would be nice if you could recruit such people and show them some work. […] Initially, a short time ago, they looked down upon us. But now it has changed in the society, we too got inured to their reaction. They had the opinion that we were disabled, what were we going to do productively? That was then, it doesn’t hold any longer. When they see us working now, it has become clear that we are equals. It occurs to us sometimes that we are more productive than many of them. […] They wondered, ‘what would we do with no legs?’ ‘How would we look?’ and ‘who would look after us?’ Even we were hopeless when they said like that, ‘what are we going to do, what do we become in the future?’ There is no employment; we dropped out of the formal education too. It was difficult with all that pressure. Once we become part of this place, that thought never runs in my mind now.

Neesha’s quote elegantly pinpoints the focus of this chapter: the significant impact ableism has on opportunities for WWD’s growth and development; and their personal feelings about this treatment. Her words address the precarious position many WWD find themselves in as a consequence of having faced multiple barriers and neglect. Neesha’s success in finding fulfillment in a skill she could use to support herself and her family was unfortunately not common during fieldwork. Her experience captures the zeitgeist many women shared related to their confidence and mission to combat and disprove harmful opinions about disability in society.
Summary

I presented themes highlighting the fragile social safety-nets many women maintained in spite of a cycle of poverty perpetuating limited opportunities for those in already marginalized positions. The nature and failures of the educational system were detailed, as were the incredibly heavy burdens these failures have continued to place on families. While women interviewed were well past primary school age, it is likely similar experiences of neglect and maltreatment persist today (Hettiarachchi & Das, 2014; Liyanage, 2017). The women could not change their past, but they were vocal about fighting for their children’s future in the area of education. Their struggles are especially salient in light of CBR’s programmatic failure to address disparities related to ableism in education and employment. It is clear policies put in place to address disability-based discrimination in these sectors have not only been unenforced, but have also completely neglected barriers related to gender. There are a clear lack of accountability mechanisms in place to ensure policy compliance.

Education is just a piece of the larger CBR matrix and is interconnected with all of the other sectors. It is impossible to fully express the long-lasting and widespread impact of the community-based disablement that the women documented. Based on the findings of the current chapter, it is clear CBR programs have not and are not doing enough to address socially-rooted issues WWD experience in relation to education and livelihood. In the following chapter, I will turn to findings highlighting social mediators of health such as aspects of kin care, unstable housing, limitations of rehabilitation technologies, inaccessible transportation, and systematic discrimination that also must be addressed.
CHAPTER 4. SOCIAL ASPECTS OF HEALTH

The land doesn’t belong to me it’s under my stepmother’s name. And now I don’t have a place to stay. I have requested from the government to provide me with a house. I’m looking into it these days since I have no proper place to stay, back then I was living well. Now, after my legs broke, I have become unable and incapable of doing anything.
(Bimali)

At the time of our interview, Bimali had built a home in a very rural area and was facing an imminent threat of eviction by her step-mother. Before a car accident that broke both of her legs while working abroad, she contributed a significant amount of her earnings to purchase land and construct the house we interviewed her in. We contacted Bimali through the Central Community Organization (CCO). During the interview, her legs were propped up on a chair, and you could see liquid had seeped from the infection through the bandages. Through her words she was strong and determined, but during the interview it was difficult to watch her pained facial expressions as she shifted her swollen legs.

Introduction

There is a dominant programmatic focus on health within a CBR context (Bualar & Ahmad, 2009; WHO et al., 2010c). The focus of this dissertation on socially mediated aspects of well-being and disability must not exclude a discussion of health. Many falsely view disability as a health issue but like aspects of disability, health is likewise socially produced and situated. Ignoring socially determined aspects of health and narrowly defining disability as a health issue falsely equates disability with poor health and poor health with disability, subsequently impacting the focus of rehabilitation programs (Lord et al., 2012). Everyone needs healthcare but PWD are subject to more intervention, impacted by inaccessible healthcare systems, and must combat pejorative beliefs held by healthcare providers that they are in some way blameworthy for their disability or illness (Fernando et al., 2010).
Sri Lanka’s community-based health programs are shaped by hundreds of years of Ayurvedic and Western practices (Fernando et al., 2003). Although the country has made significant progress on national economic indicators (Björkman, 1985; WBG, 2019), many key areas of social development must still be addressed. For example, a UN (2018) report connected low agricultural production and high food costs to significant under nutrition and anemia among women and young children (p. 16). With this context in mind, this chapter underscores health as a social process and phenomenon. The findings go beyond aspects of individual intervention, and improved functioning, toward an expanded view that considers how disabled women experience “health” and “healthcare.” In doing so, this data locates disconnects between CBR goals and the realities of women’s lives on the ground. A critical lens applied to disability, gender, and health uncover interconnecting and socially mediated issues that are almost wholly ignored and that prevent the physical and social mobility of WWD. Themes in this chapter note ways CBR may work differently for WWD and inform broad areas of international development (e.g., housing, livelihood, and access to medical care).

**Importance of Marriage and Family Networks**

Marriage is an individual, family, and community rite of passage for Sri Lankans. It can increase kinship networks, social and personal protection, and economic stability for women. Four hundred years of colonization shaped particular aspects of society, including limiting women’s autonomy by restructuring once matrilineal marriage and inheritance lines (Jayawardena, 1986; Rajasingham-Senanayake, 2004; Tudawe, 2001). Marriage is often viewed as a requirement for women and may be considered a way to channel and control powerful and potentially dangerous spiritual energy (McGilvray, 1998). A woman’s divine energy is described in ethnographic literature to be acquired through a suffering of servitude, often in relation to
marriage and family duties (Egnor, 1980). In some communities, women are viewed as incomplete until they are married and have children, “The cultural mantra among women is that a woman cannot live alone without a husband. The husband is regarded as the protector and provider for the wife” (Philips, 2003, p. 22). Widows as well as others viewed by the community to be “inauspicious and impure” (Philips, 2003, p. 25), such as those with disabilities, are banned from community-based rite ceremonies (Kandasamy et al., 2017a).

Women have specific gender roles to fulfill through caregiving (Wickrama et al., 2016). They are expected to conform to “heteronormative roles of docile daughter, chaste wife, nurturing mother, or sagacious grandmother” (de Alwis, 2002, p. 679). In this regard, disabled women are impacted in a variety of ways. For example, when “the act of ‘choosing’ is always the man’s right” (Philips, 2003, p. 22), negative beliefs and stereotypes surrounding disability may lead potential suitors and their families to falsely view a WWD as unable to bear healthy children or perform the extensive household duties of a wife (Price & Goyal, 2016).

**Structural Failures, the Burden of Care and Change**

The WHO CBR guidelines identify disabled people’s organizations (DPOs) and self-help groups as “often the best source of support, information and training for people with disabilities regarding the management of personal assistance” (WHO et al., 2010e, p. 14). Recently, disability scholars have begun to question the individual nature of empowerment discourses operating within systems rife with structural inequities (Chaudhry, 2019). The previous chapter addressed aspects of failures within the education and labor systems, and the burden such issues place on individuals and families. The current chapter brings to light intertwined structural deficits preventing those on the margins from establishing a foundation of well-being. Here, I examine primary causes of disablement: poverty, social inequities, patriarchal norms, inaccessibility, ableism, and discrimination. The primary framework of CBR, in ignoring structural variables, promotes a
singular neoliberal discourse of individual empowerment and responsibility. This focus significantly detracts from state obligations to address social and structural inequalities. Findings examine disability in conjunction with layers of socio-cultural experiences of gender. These experiences are represented through caregiving and family practices; housing and safety; rehabilitation technologies; and systematic sexism and ableism.

Findings

The WHO uses an expanded definition of health, not the traditional approach considering health as the absence of disease or illness, but as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (2010c, p. 3). CBR’s heavy programmatic focus on alleviating poverty through livelihood development programs and training, discussed in Chapter 3, are in line with this approach. However, these programs detract from efforts to address broad structural and social aspects of health. For example, an area where CBR services were effectively absent for all of the WWD was a lack of assistance with medical care. A programmatic absence related to medical care may be attributed to the government’s socialized system of primary healthcare; however, issues with transportation in accessing medical services, paying for treatment, and the low quality of care available are documented throughout this chapter.

Health and well-being cannot be attained when people do not have basic needs met such as housing, clean water, and medical care. Disability, gender, class, and geography intersect and impact overall health. It is important to consider the full range of ways systematic barriers combine to create unique and cumulative disadvantages for WWD. These obstacles, and the cycles of poverty they accompany, are far from individually produced—they are structural and systematic. Therefore, efforts geared at promoting and maintaining health and well-being require
we take a wide view of CBR and related interventions in order to consider social positions as well as individual needs and preferences. The hard work, dedication, and confidence many women shared during their interviews was tempered by struggles with housing and income instability. Accounts of poverty, inaccessibility, and discrimination were the most salient topics across all sectors and all interviews. Ways women interacted with CBR programs, navigated government benefits, and utilized family resources are featured prominently throughout this dissertation.

**Theme 1: The Importance of Kin Care**

*Women’s Work*

This section attends to women’s shared experiences of disablement in relation to social and physical location. It is important to discuss ways gender and kin care are intertwined within these contexts. A few interviewees explicitly noted the expectation for women to provide care. A powerful statement about gender, health, and care work came from Kanthi, a woman in her early sixties contacted from the SRC. For our interview we sat in chairs outside on the lawn of her newly built home. Kanthi was about to have a gathering to celebrate the completion of the primary structure. Soon they would add doors, windows, and plastered walls. Her house was an impressive two stories and she was clearly very much looking forward to the celebration. We witnessed her adult children and other family members arriving for the event. During her interview, she spoke of leaving her abusive husband while showing us a long scar on her arm. She raised her two children as a single mother with extensive support of her family. Well known for implementing grass-roots development programs in her community, I asked if there were gender differences related to her work. She replied:

> After the person is feeling better, especially women, they come back to our organization and they help us to help the other people who are suffering with the mental illness. But it
is different when it comes to males, they do not show much of an interest to join us and help the others. Most of the time it’s about 90% of the women join. Men do help but it’s about 10% of the male population who come back and join us to help the people who suffer.*

Kanthi’s quote discusses the low likelihood men would return to contribute to a CBR-type program. She also identified women as much more likely to return to assist in the program’s movement. The absence of men in social-enrichment community-based programs is problematic as it perpetuates gender-based stereotypes, and may continue to place the burden of activism, care, and social efforts on women. Vimala, the founder and director of the SRC, shared a similar sentiment when discussing her organization’s work in the community. Having worked in the CBR field for over 30 years, she detailed her continued dedication to target the attitudes of men:

…men are not sympathetic enough to, you know, to understand disability. Even in our awareness programs its more women who come, because men are at their jobs so it is not really easy. We are trying very, very, hard to change the attitude of the men also.

Vimala’s admission relating to difficulties of managing personal beliefs at the intersection of gender and disability elucidate how individual attitudes multiply and maintain social stratification along gendered lines. Her CBR program has struggled to change community perceptions and attitudes related to disability. From Vimala’s view, awareness programs that attempt to battle pejorative attitudes may be ineffective within a socio-cultural setting that maintains men’s roles outside the realm of home and kin care. The result are programs that maintain the status quo although some women have noted an improvement in women’s status over time. Vaishnavi, a widow in her late thirties, was contacted through ECBO. Her husband was killed in the war when her baby was just a few months old. At the time, her parents were too afraid to help her because she was arrested multiple times trying to go back home. Soon after losing her husband, Vaishnavi lost her father and spoke of the struggles she encountered in raising her son as a single mother. It is worth noting she was one of only two women who
successfully navigated the difficult process of getting a driver’s license although she had not
driven in a few months because her modified motorcycle required repairs. After so many
hardships, Vaishnavi was finally able to move back home and reestablish ties within her
community. She spoke of women’s changing status in Sri Lanka:

Earlier, we didn’t have any women’s involvement; we were just going to the school and
stuck at home. But these days, women, all streams of women participate. For instance, we
are there for any meetings. Our participation is much higher than men. For leadership, I
think women step up, they’ll take any leadership opportunities.

Many women echoed Vaishnavi’s statement related to women’s increased involvement in
community service, in relation to both their gender and disability status. Her comments touch on
the increased visibility that comes with being a woman, women’s social involvement outside of
the home, as well as their willingness to serve in leadership positions. Pushpa, a young woman in
her thirties, mentioned her DPO’s decision to promote women as leaders. She said men lead
many of the DPOs in her eastern area and her organization intentionally breaks that expectation.
Her DPO aims to promote the concept that every woman with a disability should come out to
help break the social norm that women should not travel away from their villages. Pushpa’s
organization decided all leadership positions should be held by women because “men are mostly
given those positions in society.”

Women are scared to “come out from the home” due to complex social issues, but Pushpa
was motivated to promote women’s status and combat gender-based gossip. She shared, “some
people say, ‘we have a problem about your husband,’ and ‘you can’t travel, you can’t go.’ And
we say, ‘No! We are able to travel! We have that ability!’ So, we do.” The role of women in the
home; their relationship between “staying hidden” and the necessity to assume leadership
positions within their communities; and combatting gender-based gossip are all intertwined.
These connections are also discussed in Chapter 3.
Importance of Parental Support

Nayana, the founder of CCO and also a WWD, noted the importance of parental support when discussing why her organization provided residential services for WWD:

The women here, they don’t have their parents. […] There is no one taking care of them, so we take care of them and look for their rights, like job opportunities, marriages, and how they can rise up in life. We keep them here because they don’t have anyone. They either end up becoming somebody’s servant or they get raped, have children, and are neglected. Therefore, we protect them and guide them on the right path here.

It is important to note gender and gender-based violence are not addressed within the CBR matrix as key areas to consider in community-based programming. Nayana directly addressed abuse in her above quote, and other women alluded to increased vulnerabilities held by women as biologically and socially responsible for bearing children. The intersection of safety, violence, and child rearing responsibilities must be incorporated into critiques of the CBR framework and CBR activities. The cascading effects of a woman’s position as biological reproducer impacts all areas of her life, not to mention all aspects of her health. Nayana (CCO) and Arunadhan (NVCC) led programs that were selective in taking women into their residential services. Both cited an endless need within the community to provide safe housing supports for women. Factors contributing to the great need for residential services involve the hardships of being single women struggling financially in a society where a woman’s position is typically not as an income generator.

The interwoven nature of marital status and poverty are especially salient for WWD. Thirty out of the 46 women interviewed did not have husbands (either due to being divorced, abandoned, widowed, or never married). Eleven supported themselves, their children, and sometimes aging parents in what would be considered a “woman headed household.” Seven women were unmarried and lived in dormitory style housing. Ten women were single and lived
in a family member’s house, supported by parents or an older brother. Two women, single without children, lived in their own home. Sixteen women were currently married. The majority of currently married women lived with their husbands, but one chose to live in the CBR dorm where she worked because her work was far from her village. Many, regardless of spousal status, cared for aging parents within their household in addition to children. Some description of interviewees quoted are presented in Appendix C.

Women often provided kin care in the form of caregiving for children; performing daily chores such as laundry, cooking, and cleaning; provision of food and housing; and caring for aging parents. Many also expressed receiving support from parents, children, husbands, co-workers, neighbors, aunts, and grandparents. These exchanges of support were often bi-directional and multifaceted. The complex informal social networks described throughout this research were often characterized by unrecognized expectations of care. There is a need to discuss ways gender roles work within day-to-day family operations, both in relation to expectations of men to provide for families financially and of women to perform all aspects of household and family labor. This gendered care expectation that women stay within their homes may lessen the visibility and value of their contributions at a societal level.

Chamari, in her forties, was contacted through SRC. She worked hard in the labor and manufacturing sector to provide for her children. Like many of the married women, Chamari’s husband also had disabilities. His asthma, vision, and back problems occasioned high medical costs and intermittently impacted his ability to work. We sat on wooden upholstered furniture in her living room with the wind occasionally directing rain to fall on us, past a thin fabric window curtain and on to the couch where we interviewed her. Their home had clean dirt floors and unplastered walls.
Chamari often redirected our interview in order to detail the financial difficulties of paying for her husband’s medical care while trying to improve their home. Even though her home was not yet completed, she aspired to build another home for her son’s future. Home improvement and her husband’s rising medical bills were the major reasons she had taken out multiple loans. It might be assumed Chamari and her husband will live with one or both of her sons and their wives and children until they die; therefore, building a home for her sons is not only a short-term goal but also a long-term investment for old age. If her son has a completed home, “they would only need to worry about earning for their food.” But her husband’s illnesses created unexpected costs, and their outstanding loan payments were a major reason they have so far delayed getting him more treatment.

Life-stages of WWD are important to note, particularly within the context of this chapter. The experiences of women must be viewed in light of gender norms, age, and family status. At least a dozen women noted they felt encouraged by their families and highlighted psychosocial aspects related to the types of non-material support they received. A few mentioned how, when growing up, their parents and siblings “treated them the same as” and not like someone with a disability would typically be treated. However, reflections of being treated the same were not common. More often, women found themselves in adulthood with few avenues for social mobility related to education, marriage, and livelihood.

Women’s economic and social burden becomes two-fold in adulthood, with expectations to care for both children as well as aging parents. If they lost their parents, or were single mothers, like many in this research, they heavily relied on siblings as sources of support. Many received help, often from brothers, for housing costs, physical assistance for mobility, and support for their children. Assistance from male relatives often took the form of regular financial
contributions for the provision of food, clothing, and education expenses. Support provided by women, such as sisters, sisters in-law, mothers, and grandmothers, was widespread and took multiple forms. Help included meal purchasing and preparation, household chores, and childcare. Eleven women directly detailed resources they received from their mothers while many more, 22, possibly due to the loss of parents, noted extensive supports they received from siblings.

Based on themes evident in the data, this chapter positions health as directly mediated by a multiplicity of social factors that determine overall well-being. Gender impacts everything about health and access to food is one example. Aside from the provision of food for residential WWD, health in relation to nutrition access for women was not mentioned by any of the CBR programs. The CBR framework fails to address structural limitations relating to the role of gender and nutrition within programs. This is important in the Sri Lankan context as the prevalence of nutritional deficiency is a major concern (UN, 2018, p. 16). It is also necessary to consider prominent expectations that women perform household labor; the impact of their home confinement; and few available resources to navigate structural barriers (e.g., inaccessible public transportation).

Women often discussed their struggles to provide for their children. Many also noted the ways their children helped them. Lalitha was in her sixties and more of her background is detailed in Chapter 5. She hoped the shop she started with the help of a CCO loan would make more money soon so her adult children would not need to worry about supporting her:

They also don’t have jobs. They live in difficulty. When they earn, they give me something to keep. When I’m sick, they take me to the hospital and get medicine. But after I started to do this, I don’t worry them.

Maheshi also had a store she developed with the help of a loan from CCO. Since childhood she had struggled to secure balance while walking. When we spoke with her in her
store, she was seated and unable to walk very well because of a swollen ankle she accidently injured when working in the garden a few weeks prior. Maheshi’s shop was very organized and well stocked. For the hour-long interview, her younger adolescent son sat near us while her teenage daughter ran the shop and interacted with the few customers who came by to make a purchase. Maheshi detailed the many ways her daughter helped her:

Before I started the shop, my daughter picked leafy vegetables for us to eat. She would pick them and tie them together and sell them. My daughter would ride a bike and sell vegetables to each and every house. She was about to sit for O-Levels this year, but because of an error in her birth certificate, with one letter wrong, she couldn’t apply for the exam, so she has no school this year. That’s why she’s helping me. She helps me cook and clean and is in the store from morning to evening.*

Many women mentioned their children provided direct physical assistance, for example in relation to toileting, grocery shopping, or cooking. Others mentioned their children would help take them to doctor’s appointments; get medicine; provide money; and/or help with income generating projects, such as stocking or working inside their small storefront. Many expressed their reliance on others in terms of physical accessibility and cost-related issues with using public transportation for travel. The necessity to carry heavy bags while using public transportation was especially difficult during busy times, where seating, storage, and often safe standing space for passengers was very limited. Praveena lived in the eastern region and mentioned she must ride the bus while holding on with both hands. For her, not getting a seat was problematic and made it impossible to carry necessary items. She had recently fallen down and was injured on the bus so she is now more adamant about getting a seat from fellow passengers. In response to frequent protests from people who said no when she asked for a seat, Praveena exclaimed:

What shall I do if they reject me or they say no? What shall I do? I can’t stand. Everyone will put down their heads and look out. We should ask, we should express our problem. I have to sit down, otherwise if they brake suddenly, I will slip.*
Almost every interviewee echoed Praveena’s descriptions of unsafe and inaccessible transportation. The impact of rurality and a lack of transportation are evident throughout this dissertation. A few women proudly shared they traveled alone on the local bus to the market and back to purchase what they needed for their home business or household. Others mentioned they easily purchased their provisions through mobile vegetable and meat sellers who drove by their homes and through their neighborhoods.

In addition to having a kin network that helped with shopping for vegetables and food, many women relied on family members to cook in the kitchen. Shamini’s brother went even further. In addition to financial support, “he makes sure that we’ve had a wash and are dressed. He visits regularly, whenever a need arises, he comes.” Although having siblings does not guarantee assistance. For example, Amanthi, with eight siblings, said if she was going to tell the truth, “the others don’t care that much. Only this sister is taking care of me.” Thivya, whose experiences of dealing with housing corruption are detailed in Chapter 5, praised how much her family helped her with recovery from significant infections acquired during the war:

My family, they all took care of me very well. I had the operation and then this big wound. They cut here, and they cut here, and they cut here. Everyone, my younger brother came here. He would just carry me like a baby. At the time I was continuously bleeding, for two months. That was a huge problem, so they carried me to go to the toilet and everything. If my mother was not home, other people dressed me and they made my hair styled and everything. My younger brother, he cooked everything and he fed me. They cared for me very well.*

Although Thivya’s family had lost their father very early in the war, they managed to help her with recovery and reintegration from the army camp. She was not married and when I asked why she exclaimed so many people ask her that question. She detailed that first her brothers will get married and then if anyone should come to marry her they should understand her needs very well, otherwise, she fears being abandoned as a single parent because “even non-
disabled women face the same problem.” Thivya’s fears of ending up alone were relayed by many women, on one hand, regarding what might happen to them after their parents pass away and they are unmarried, or, on the other hand, in relation to marriage and the potential for maltreatment or abandonment by their husbands. As mentioned, marriage and family play very important roles in determining women’s social and economic well-being. The next section furthers this theme of worrying about the status of their future.

“Who Will Look After You?”

A major theme related to messages WWD received around love and marriage, strictly mentioned only in terms of heterosexuality, encapsulates the inevitability of a precarious future. Both Nayana (leader, CCO) and Ramesh (leader, ECBO) discussed improvements in the status of WWD in some sectors over time, such as employment and trainings, but also noted there had been no progress in the area of society accepting the desire of WWD to marry. Marriage is a major social institution, and gender roles center on the expectation that women find a male protector, get married, and work in the home; yet many women discussed messages from family and kin networks encouraging them not to get married.

A handful of women expressed the wish to get married in conjunction with wondering what might happen to them after their parents passed away, while a few spoke of fearing marriage. Their fears specifically centered on links between disability, gender, infidelity, and abandonment. For example, when Nayana was young she wanted to get married but her family instilled a fear in her by saying, “you are disabled, your husband will leave you.” Kumari, who married when she was older said, “I was afraid to get married because I had an aunt who had polio and she was cheated on by her husband and therefore I disliked marriage.” These messages from family created trepidation and mistrust among WWD related to men, love, and marriage.
Women also spoke of the powerful influence a potential partner’s family holds over their marriage prospects. Hiruni, in her early thirties, was living and working at CCO. She wished to get married but found it hard to locate a good match because, “the man who finds proposals, the broker, he never tells the family that I’m disabled. So, they come and only then they find out that I’m disabled.”* Ajanthani, also in her thirties recently started working at NVCC. She felt the most striking gender-bias was related to disability and marriage:

> The disabled men, they can marry a girl no problem because of our community. But if a disabled woman wants to marry a man, they ask further questions […] they think disabled women are not capable for them. The wedding is the major problem because the men’s side of the family, they can’t accept a girl as a disabled wife.*

As Ajanthani detailed, the impact of families in approving matches cannot be understated and WWD are often placed lowest on the decision-making chain. Due to financial reasons, many resided with parents or siblings and wondered out loud who would take care of them once kin were no longer able to support them. Consequently, marriage and children (who will one day grow old and support their parents) are reasonable solutions to the questions society places on them related to who will care for them. Only a few women went against the grain and outwardly rejected the assumption that they are in need of custodians.

Thilini was in her fifties and lived with her mother. She lost two brothers during the war and her father to illness. Even with her losses, she had a supportive network of kin in her village. Content with the way she lived, unmarried and happily living with her mother, Thilini, along with five other women (in direct contradiction of strong pressures for male guardianship) expressed they “can be alone”—an uncommon sentiment in asserting their independence as capable women thriving within networks of supportive communities. In the next section I transition to another prominent theme in the data, experiences of unstable housing. I describe the
fourth field site, the Central Community Organization (CCO), in detail and then discuss ways housing issues intersected with gender, disability, and movement.

**Theme 2: Housing Instability, Gender, and Freedom of Movement**

The strength of WWD and their commitment to serve the community through meaningful engagement is reflected in the work of the Central Community Organization (CCO). As mentioned in Chapter 2, I first spoke with Nayana, a WWD and the leader and founder of CCO, at a restaurant down the street from my house. Although she did not remember me then, I recognized her from an earlier professional training about inclusive research with PWD that took place many months prior. She was at once reserved and responsive regarding my research purpose. Her stature promoted listening and reflection far more than talking, and I was incredibly grateful when she agreed to host my research and participate in an interview about her experiences as both a leader and a WWD.

CCO was located about a twenty-minute walk from the nearest highway and an hour by bus from the nearest town. The bus stop was on a busy highway with one small storefront selling nonperishable household items just across the street. Considering my housing troubles in Colombo, I was grateful CCO provided a bedroom located at the center. After stepping down from the bus I crossed the street to purchase toilet paper only to find the next best thing, a pack of dusty napkins. I crossed back again and walked down the road after locating a small sign that indicated it would lead me to the center.

The road was picturesque. It was midafternoon and the light was softly filtered through a tree-lined green canopy. The pavement was uncommonly smooth, a recently completed blacktop. Even though there were no sidewalks, each side offered plenty of space to step aside in the event of traffic, but I did not encounter anyone on the quiet road. I passed the occasional Hindu shrine,
along with a handful of quiet homes. I was awestruck by the sounds of nature and how beautifully the trees framed the road and grew with their unique curves and knots. After 30 minutes of walking I turned around, assuming I passed my destination. Backtracking around half a kilometer, I saw a large faded sign with illegible writing. The space was quiet but I thought it must mark the place. I walked slowly down the compact dirt driveway and went to what appeared to be the entryway to a central location, a one-story house. There were multiple buildings visible on the property but the paths to their entrances were covered with overgrowth and their doors appeared to have been shut for many years.

After locating the office and engaging in greetings I was shown to where I would be staying. We walked down a dirt path from the main office, past the unused buildings, gardens, a mangy dog, and then onto a paved ramp that led to a covered veranda and entry way with many doors. One was the entrance to my room and another led to shared dormitories. I stayed in an annex connected to the dormitories of the women staying at CCO. My room was located outside a set of double glass doors that were often secured from the outside using a loose chain and a padlock that held the appearance of being fastened. The women staying there were “those without parents” with mild to severe MI/ID. They gardened, performed household chores, prepared food, and watched television at night. Although I did not interview any of the women with MI/ID living there, I did interview three women working at CCO. We all became acquainted through our daily interactions and close living proximity. Occasionally at night I would hear someone wake up from a nightmare only to be soothed by the others soon after. One night, I heard loud bangs and was informed it was someone in the village scaring off menacing elephants.
I interviewed 11 WWD affiliated with CCO. Three lived and worked on the campus, some were from nearby villages, and others lived in different districts over an hour drive away. My experience of living at the center highlighted its unique nature. I was privileged to stay there and make connections with the women who lived and worked there. Observing CCO’s residential services, while interviewing women from all over the region, highlighted how different the program was. The center was enmeshed with the local villagers, including a few who came to the veranda to ask what I was doing there. Unlike many of the other sites and homes I visited, there was no large gate or protective fencing. The most notable aspect of the setup concerned the absence of men. Women ran the grounds and based on my time there they appeared to be just fine doing so. Everyone on the campus, including the leaders, were WWD. The psycho-social impact of a model that promotes and includes WWD in leadership positions is reflected in some of the interviews, particularly from women whose families had not “pushed” them growing up as children with disabilities. The center, run by WWD, had taken on the role of “looking after” WWD with MI/ID. In doing so, they addressed a significant issue discussed more in depth in the following section: housing instability.

**Housing Instability**

CBR often locates the prevention of illness and promotion of health from an individual standpoint. This is in spite of evidence that shows a clear need to expand the concept of intervening on individual health toward broader changes that address systemic and socially mediated barriers to well-being. Women interviewed for this research did not appear to have much impact in determining the role of the CBR programs in their lives or on the development or re-direction of CBR efforts toward person-centered goals. Many discussed wanting to improve their homes. A major aspect of health the women often circled back to in conversation was their
housing status: incomplete, precarious, unstable, or difficult to manage. Kumari noted the greatest issue WWD encounter concerns their care and safety. She worked at CCO assisting women with MI/ID who lived in the dormitory. This work experience likely influenced her recommendations for improvement. Like many interviewees, she described the uncertainty WWD struggle with when their parents pass away, especially if family members may be unwilling or unable to take on the responsibility of caring for them. When this happens, Kumari noted it can be much harder for women:

A man can stay anywhere after going. Even under a tree he can stay. Someone will give him food, but a woman can’t. [...] Now when you take a woman regardless of her been disabled or not, she cannot go alone on the road, can’t be alone. So, a disabled person has more problems because they can’t come and go freely, run, communicate or understand properly. A normal person can talk about it or find their way back and take precautions. [...] Even men can have these issues, but women face more of a risk. [...] We don’t like to stay alone at home locked up. [...] The food is not given properly [...] they don’t like to keep them nor do they like their kids to interact with them.

Kumari’s quote describes many of the social issues that prevent the freedom and mobility of WWD. At the end of the quote she notes the impact of being confined to neglectful homes that may mistreat women because of their disability. The work of CCO is closer to a custodial model of care than the training model described at NVCC, although Nayana (CCO leader), like Vimala (SRC leader), noted their organization made efforts to find suitable marriages for WWD in order to improve their social and material status. As discussed, marriage can impact multiple areas of well-being, not only in terms of women’s freedom of movement but also in relation to financial stability, housing, and security.

Eligible recipients for housing grants must have land in their name and buying land was likely prohibitively expensive for many women. In addition to having a land deed, some women noted the requirement to be married before they could receive a grant to build a house. During our interview, Thivya told us she had concealed her father’s name by covering it with a
photograph over her framed housing certificate. He had been listed as her husband on the certificate and that slightly embarrassed her. Most of the women interviewed in this research worked within top-down systems of interventions. They had very little impact on the design of community-based services. For example, the community programs included in this research were designed and implemented using a predetermined template set forth by funding agencies, instead of being designed via local or individual authorship. The women interviewed in the current research did not have an impact on the framework of CBR services, but women like Thivya, whose experiences are detailed more in Chapter 5, employed “strategies of resistance” in order to achieve her goals and influence her community (Senier & Miranda-Galarza, 2016, p. 401).

Some women received land as a wedding gift, while others were gifted or inherited land from their parents. Two noted the finished status of their homes detracted from provision of much needed financial assistance. Jayanthi, living in the central region, said she was rejected from receiving private and government donations because she has “a roof over her head.” Shamini, introduced briefly earlier, expressed the tremendous support she received from her older brother who lived nearby with his family. The home Shamini lived in, along with her husband, ailing mother, son, and adult brother with multiple impairments, was completed years earlier when her father was a government servant. Details like this locate dominant positions men hold in society as resource bearers, noteworthy here as in direct contrast to those not held by women. They provide grounds to examine and critique allocations of capital on the basis of gender. As detailed in other chapters, gender impacted the types of jobs women could get as well as their roles within household labor. Shamini’s experiences with disability-based employment discrimination are also discussed later in the chapter.
Like another interviewee whose father passed away after years of government service, Shamini’s mother did not receive the promised pension. On top of financial struggles, she and her brother (both coping with degenerative diseases) were ineligible for disability-related government assistance because their father had been a government employee prior to his death. She said, “the house was built when my father was alive, when my parents were capable. But now, we don’t have an income like before. Our current income isn’t enough. Expenses are too high because of the disability and our problems.” After her father passed away, she spoke with two government employees who rejected their application for assistance because they, “judged and measured their level of need based on the furniture in the house.”

Many interviewees directed the topic of conversation during their interviews to discuss housing concerns, or for those living in dorms, their desire to move back home. Many mentioned wanting to improve the quality of their home, such as an addition of cement floors or plaster, or building interior bathrooms with toilets. Some lived in areas subject to heavy flooding, landslides, and rain. Roshani, quoted earlier about her experiences of neglect by teachers as a young blind student in the 1970s, lived in one of the homes the most visibly in need of completion and repair. Many lived in houses without paved floors or window frames. Although this may be a reflection of sampling due to recruitment methods, it is important to note. Many had received financial assistance to improve their homes. Some accepted small grants from CBR programs for housing improvements, while others received large sums of money from the Indian government or Sri Lankan government to build a house. A couple of women referenced Sri Lankan government housing schemes targeted directly toward PWD. Others benefited from an Indian government program for people displaced due to war. Many more women did not receive housing assistance and lived in a CBR dormitory or in a family member’s house.
Roshani and her teenage son were living with her sister’s family but our interview took place inside her damaged home. We met her at her sister’s home and then travelled a few kilometers to reach the ancestral house she had once lived in. Roshani and her son had not been able to live in their home since the last storm and she hoped to make improvements soon. Of all the women interviewed in their homes, hers was by far the most in need of repair. The walls and furniture were mildewed due to open window areas and portions of the roof and walls had deteriorated away.

Roshani hoped she and her teenage son could soon move out of her sister’s house and back in the home her mother gave her once she was able to earn a living and pay for necessary improvements. Although not currently making an income, she was optimistic about the future potential of a cinnamon growing project she recently started using a grant from SRC. More about the experiences of women’s struggles to find work are detailed in Chapter 3. A handful of women in the east lived in homes that were damaged by the tsunami. Like the women in the south, they also noted significant structural issues caused by rain and flooding as well as a lack of potable water. Praveena, in her late thirties, was interviewed through ECBO. She built a portion of her home through an INGO tsunami housing project although noted the slant design of the roof leaked water into the house when it rained.

Praveena and Priya were the only pair of sisters interviewed. Priya, the older sister, was in early adolescence when she started to fall down while walking. A few years later, her sister Praveena also began to experience strength deterioration in her legs and overall fatigue. Priya, lived with her husband, two adolescent children, and mother. Her mother’s parents originally used the land for livestock. Priya and her husband applied for a loan to finish the house and she said she felt very lucky their home was one of only three in the village not destroyed by the
tsunami. Many neighbors slept there during that time. Priya felt very blessed when their well held-up to the storm and contained drinking water “because I can’t go somewhere else to fetch the water. Our water was the only clean one, except for ours, all the others spoiled.”* Her well was the only one in the area not contaminated so they opened it for the neighbors to use. Like Priya, many women were physically unable to carry water in their arms while balancing to walk safely in their villages. Women’s extensive labor in relation to retrieving water is important to note (Tudawe, 2001, p. 32). Many lived surrounded by uneven roads and walkways, and the water needed to provide for a family’s needs would be too heavy to carry safely. Maheshi, introduced earlier, received help from her daughter. She relied on neighbors for access to clean water when her children were small. Back then, she went to the neighbor’s and carried seven big pots of water back and forth every day for bathing, cooking, and washing.

**Women and Water**

Access to clean water is essential for prevention of illness and maintaining health and well-being. While many women did not discuss access to clean water as something they struggled with, four interviewees across three geographical areas experienced water insecurity. One woman living at the top of a steep hill said in the dry season if they have not had rain for a week or two they run out of water for four to six days. This water shortage makes it really difficult to cook and complete household chores. With her daughter, toddler grandson, and husband all living there, the family requires a substantial amount of water for laundry, cooking, and other household activities. SRC gave her Rs.100,000 to cement floors and plaster the walls of her living room and she hoped they would also help her with water access.

Pushpa, who we met through the ECBO, received a small monthly allowance to purchase drinking water and medicine for her husband who acquired a spinal cord injury during the war.
He can only drink more expensive purified water due to his susceptibility to infections. For the last two months he was receiving treatment in a hospital a few hours away. Pushpa mentioned that even though they both have significant disabilities they are only allowed one Rs.3,000 a month per family in disability assistance. References to government disability-specific assistance programs were rare during the interviews. Instead, the vast majority spoke of “Samurdhi,” an assistance program based on family income alone. Samurdhi is a Rs.3,000 a month stipend for some families who make under Rs.4,000 per month. Issues with administrative discretion of social protection programs such as Samurdhi have been documented in research (Bandara, 2016; Samararatne & Soldatic, 2015; UN, 2018), although further studies should more closely examine the welfare system and its impact on families.

Pushpa and her husband learned through a friend they could receive a monthly grant of Rs.10,000 from an INGO to supplement their income because her husband is unable to work. They also received another grant to make their bathroom wheelchair accessible and now it is “big, just like a living room.” Other women noted accessibility issues while using the bathroom inside or near their homes. Priya, one of two women in the sample working for the government, struggled with the inaccessibility of her bathroom. The interior of her home was completed but she mentioned their toilet was located in a separate structure outside her home and was very difficult for her to use. Her family of five use a scrub, or squat, toilet. This type of toilet is typically characterized as a ground-level receptacle with cement or porcelain foot placements over an inset bowl in the ground. Scrub toilets require squatting and significant bending of the knees to use. Priya must stand while holding a rope for balance in order to use her scrub toilet:

As a woman I face many difficulties. […] I struggled a lot. I suffered a lot during my pregnancy. Normally pregnancy is a struggle with the baby, but for me it is even more difficult. I couldn’t sit on the scrub toilet so it was a big problem. We thought of planning for another child but my husband said, “No you struggle a lot. I couldn’t tolerate your
pain and suffering, so it’s a no.” We just thought, with two girls, if we find a third child that is a boy, that’s good. But we don’t know if we get a girl. If we get a girl that might be a little bit of a struggle. Finally, we decided, okay, it’s no problem. We are able to look after them very well, these two.*

Priya’s experiences with inaccessibility, compounded by pregnancy, illuminate areas where gender and disability intersect and must be viewed in conjunction. Many other women noted difficulties when going out in public because there were no accessible toilets for women to use. As detailed throughout this dissertation, public access is already difficult to manage due to numerous physical and social barriers. Details of limited water access are especially salient in relation to women’s roles as laborers within the home. It is typically their responsibility to fetch the water used for various household tasks in order to maintain the family. These complex sets of structural barriers impact opportunities for women to maintain their health and the health of their families and must be discussed within a CBR context.

So far, this chapter has provided data to highlight foundational socially determined building blocks for health—access to housing and clean water. These larger structural issues prevent WWD from accessing basic needs. They may not be immediately considered as aspects of health and well-being within the purview of CBR, but they should be. The next findings section moves this macro line of analysis toward the more personal, although still institutionally determined, bodily and material experiences of assistive devices and rehabilitation.

**Theme 3: Limitations of Rehabilitation Technologies**

The programmatic scopes of the Northern (NRC) and Southern (SCR) Rehabilitation Centers were wide-reaching. Women interviewed from other CBR sites across the country noted they interacted with both centers to receive prostheses or assistive devices. The programs mostly worked to increase the physical mobility of PWD through rehabilitation exercises and prosthetic/orthotic development. My initial encounter with NRC is detailed in Chapter 1, and my
experiences of trying, and failing, to observe their center and community-based work are noted in Chapter 2. As NRC was the first site to agree to host my research, there was admittedly an adjustment period on my part. Observing one clinician who took an affinity toward me comprised the majority of my participant observation experiences within NRC. During the few instances I was invited to observe her, we went to the back of the building and into an empty assessment room. The room had three small patient beds, two office desks, a sink, and multiple chairs. Pieces of unused and expensive looking exercise equipment were stored in the room, along with a very nice rolling desk chair tucked away deep in a corner. The shelves were lined with children’s toys and activities, all organized neatly. The wall behind the toys had a colorfully painted cartoon mural. Another contained posters of the body that documented physiological information about the heart, back, and skeleton.

Most of the clients at NRC appeared to be adult males. However, during one observation the clinician instructed college students to safely perform physical therapy exercises with two young children who had feeding tubes and multiple disabilities. For the majority of my time at NRC the interpreter and I were seated outside of the main entrance to the offices. In many weeks of visits to NRC we were only able to recruit four adult women to speak with us, many who attended the CBR center for prosthetic devices.

Prosthetics and Braces

Data presented in this section highlight ways assistive devices and prostheses, often seen as the solution to overcoming multiple barriers, may inadvertently create new and different problems in the women’s lives. These experiences also require a critical examination of the meaning of health, mobility, and optimal functioning. We must also ask about the ways these personal yet shared societal obstacles alter notions of overall well-being. Sharona, mentioned
earlier, lived with her toddler son and husband. Like many families they were struggling to improve their home. They received a grant from an INGO to build a house in a rural location and the funds were not enough. She discussed working in phases to complete their home. Flooding up to their knees outside of the front door in the rainy season presented a significant problem, especially with a young child. She told us about their request for a government assistance loan program to build water tanks and a bathroom:

We came to the AGA office to file some documents, to get me a prosthesis, and they connected me to an organization who quickly came to inspect the house. Within the span of 16 days they gave us the money to renovate our house. We did what we could with that money. It would flood to the knee level sometimes. We suffered that way. Then we got some loans to overhaul it. I have troublesome legs, they go numb, so we needed a commode and a water tank. They encouraged us to build a toilet and said they will give us a loan for Rs.50,000 after. So we pawned in order to build the structure for the toilet. But they reneged on the loan promise. Stuff we bought for the toilet is still here, having not been implemented for about one and a half years now. [...] It’s very difficult with a child. Since we renovated that, we were able to keep him (pointing to her son) safely in the house last monsoon. He had already started to go towards the flood, which is up to your knee. That’s why we also started building the bathroom, but we couldn’t finish it.

Sharona, like many women, was expected to perform particular types of labor related to the domestic sphere of the home. These roles are particularly difficult to fill when homes and environments are not designed for accessibility and instead with an assumption of able-bodiedness. She wore two prosthetic hands and forearms due to the war and noted problems with using the NRC prostheses, as did multiple women. She also spoke of difficulties performing her care role as a wife and mother. Her family hoped to get a washing machine to ease with the daily chores. She is expected to complete the cooking, washing, and cleaning. Her husband helps with some chores but he works during the day as a cement laborer. Due to the nature of his work he has wounds on his hands that make it painful to help with clothes washing. Sharona and her husband did not have the help of nearby parents or family. This left her with plenty of work to do, especially while caring for a young son. She noted her hand and arm prostheses were made
by different organizations and the poor quality of the hands made it very difficult to sweep and perform other routine tasks during the day.

Sharona did not pay for her most recent prostheses, but told us the program informed her she would have to cover the costs of her next set. She is happy with the way the forearms work from NRC but wished to change the hand attachments for increased functionality and comfort. She wanted hands made of more flexible material so she could manipulate and reposition her fingers. She said this would make the device more useful. Sharona referenced other prosthetics she had seen that easily held and manipulated items such as a spoon or a broom. Those were unlike the stiff fingers and hands provided by NRC that made it “difficult to hold anything.” Her arm prostheses appeared a bit too long for her frame, with extra plastic jutting out from her elbows, and the glued-on hands were easy to discern because they were a different shade and much lighter than her natural skin tone. When I asked why she had not been able to get the hand attachments she wants, she noted:

Earlier, they had only one prosthetic for each arm like this here, which they gave me first. Now, they don't have those. However, they are producing prostheses themselves here. You can’t do anything with those, can’t even grip a spoon for instance. Even they admit it. It’s only for aesthetics. [...] I haven't gone to collect the new one from them yet. I was supposed to go there on 13th but the motorbike broke down. This one, they made this for me but it’s too tight.

Sharona lived in a rural location with her young son and no form of transportation. Her remote homestead made it difficult to attend fittings and other appointments. Her experiences with poorly designed prostheses problematize ways rurality and poverty influence technologies and basic mobility. In addition to ill-fitting prostheses, other women reported theirs were too heavy to benefit them fully. Jaana was in her late twenties working at NVCC. She also wanted a different prosthesis than the leg provided by NRC because the prostheses damage easily and require replacement often. Prior to the war ending, she had access to better quality imported
prostheses that were easier to use. Once she complained the leg was too heavy and they told her there was nothing they could do because they “no longer receive assistance from abroad.”*

Another interviewee, a widow in her fifties, received a leg prosthesis from NRC. She also lamented the heaviness made it uneasy for her to walk. She tried to get help from the local government and NGOs for a better device but had not been able to locate anyone to help her.

Priya worked in a government school in the east and lived with her mother, husband, and two daughters. Her mother cooked for the family of five while she worked all day. During our interview, she showed us the leg brace and modified shoe she wears when she leaves home. When asked about transportation Priya mentioned her neighbors were very supportive and would often come by her house to offer her rides to work. Earlier programs provided socks for her to wear, but now she was expected to pay for them. She felt lucky to have a lighter leg brace compared to the iron ones she used before saying, “I can’t walk without them. Here is my scar, and still I wear them. If I can’t wear them, I cannot walk.”*

Tabitha, also in the east, was happy with the quality of her leg prosthesis from NRC. Her leg before was 2 to 3 kilograms and her current leg is only 1.5 kilograms. She gets a new leg every three years and a new foot once per year. The man who made her leg also has a disability and has known her “since the beginning,” so he knows well what she wants. While Tabitha noted she was happy with the weight, she also brought up issues with wounds related to using heavy prostheses. She underscored the importance of wearing socks but even still had to wait sometimes for her wound to cure before she could walk again. The next section explicitly highlights limitations of rehabilitation technologies. The findings concern the disconnect between CBR goals and the realities interviewees shared related to physical rehabilitation and assistive devices.
Physical Rehabilitation and Field Officers

The traditional role of field officers (FOs) in CBR is one centered on community-based outreach for health education. Historically, they aimed to address gaps in medical access for rural communities and focused on educating families of PWD regarding physical rehabilitation exercises (Helander et al., 1983). The role of FOs in this research has been a questionable one. NRC technically employed one but his work in the community was never observed or noted on by the interviewees. NVCC did not have FOs. SRC was the only site with multiple FOs, although as detailed below, the FO’s work with the women interviewed depended on the background of the FO. I met one FO working with CCO, although it is unclear if he played a specific role in the interviewee’s lives. ECBO did not appear to employ FOs; however, some women interviewed from that organization mentioned they had been hired intermittently to work part-time on community-based disability related out-reach projects.

Many community leaders noted the decrease in international funding over the last 10 years resulted in only a fraction of their FOs remaining active. The work of FOs carries high over-head employment and transportation costs and is considered expendable compared to center-based work that occasions less community-based outreach. I observed that women’s differing experiences related to CBR services were directly linked to the skill-set and experience of the FO assigned to their region. SRC’s FOs visited some women’s homes monthly to check on them. Women noted FOs helped them with housing grants, physical rehabilitation exercises, or livelihood project development; however, assistance across multiple sectors rarely overlapped for any one woman. The minimal role FOs served in the current data misalign with the community-based mission of each field site. Many leaders attributed this to a necessary result of funding scarcity when asked about this discrepancy.
Many women from SRC were visited by FOs even during a time of low-funding. One exclaimed she was only able to get out of bed and walk again because the FO came to her home to provide physical exercises. Her experience of transformational rehabilitation provided by a CBR program was unique. Women were more commonly unaware the CBR program provided physical rehabilitation exercises. When asked if SRC helped them in this way, as they did for some women, many said they did not. Some informed us the government hospitals, often far away, had better rehabilitation programs, better technologies, equipment, and exercises than their local CBR programs. For example, one woman contacted from SRC completed six weeks of physical rehabilitation at a faraway hospital. Even though some of the hospital’s equipment was in disrepair during her stay she noted it was still better than that at her local center. She questioned if she could have made more progress if she went earlier to the government hospital after her stroke.

This section detailed how limited rehabilitation technologies impacted many of the women’s day-to-day lives. CBR programs provided assistive devices; however, there was significantly less of a programmatic focus on health and physical rehabilitation relative to what was expected based on previous research (Bualar & Ahmad, 2009). Women often lamented the technologies available to them were subpar and hindered optimal mobility and physical functioning. These results provide clear evidence of a need for improved rehabilitation services and technologies. Improvements in this area must necessarily coincide with a more holistic view of health and well-being. The next and final theme discussed in this chapter widens the scope from deficit-based individual rehabilitation technologies toward details of widespread ableism, discrimination, and inaccessibility that impeded women’s opportunities for employment, mobility, and healthcare access.
Theme 4: Systematic Discrimination: Pervasive Ableism and Inaccessibility

For 10 years I was tricked saying I will receive a government job although I didn’t. […] When I filled out applications, I didn’t mark that I’m disabled, there is a field to mark if you are, but I filled it as a normal person and not disabled. Because there is discrimination when they notice you are disabled and therefore, they reject your application. (Kumari)

The themes detailed in this chapter identified foundational social issues in the women’s lives that increased their struggles for well-being. Direct experiences of family, housing, and physical mobility can either alleviate or hinder opportunities for WWD to secure health and stability. The next section draws on findings related to infrastructural elements of health, gender, and disability-based obstacles. The following section briefly details employment and driving discrimination, an area where the enormity of the impact is difficult to gauge. Increasing the mobility of WWD through driving would likely alter many barriers women discussed relating to provision of kin care, employment, as well as social and physical access and inclusion in their communities. This impact is only speculative and the potentialities involved in women’s mobility through licensure should be examined in future research and practice.

Disability-based Employment Discrimination

Kumari, quoted above, spoke of systematic discrimination when she applied for government positions. She was determined to apply for many years but eventually gave up after she surpassed the maximum age limit. Research from Biggeri and colleagues (2014) in India echo PWD’s feelings of frustration related to limited job opportunities relative to their non-disabled peers (Biggeri et al., 2014). Other women interviewed noted the medical exam required by the Sri Lankan government in order to apply as a job candidate was discriminatory.

Shamini, introduced earlier, used a wheelchair for mobility outside of her home but rarely went outside. She lived with her husband, 11-year-old son, mother, and a younger adult brother
who also had a disability. Shamini attended a few trainings offered by SRC and spoke constantly during our interview about her skills and desire to work. She tutored students on computer programs prior to her illness; and now made many beautiful handicrafts that were difficult to sell.

When asked how Sri Lankans’ viewed disability, she answered:

> Some people are willing to help, but most of the time people say “you can’t” and “no” as an answer. As an example, I was looking at job providers online and I called and really inquired about a job, and then the person who answered the phone told me, “it’s for normal people.” I said, “am I not a normal person?” Then she said, “no, this is for normal people, not for people like you. Because it’s difficult for you all to work.” I explained that wherever they conduct the registration process and the training that I would come, but the person on the phone said most of the time the trainings would be conducted in an upstairs building and I wouldn’t be able to go. But I said, “it’s okay, I will ask someone to come pick me up and help me out.” But she said, “no this program is not for people like you.” After that I have not called them back. […] There are a lot of people like us, even though we have the abilities, we can’t get a job. I have the idea that the government should give opportunities for people like us, but we don’t get an opportunity. […] I have applied for government jobs with my bio data. But in our country, there are no opportunities […] and also, they say I have failed medical tests. […] We don’t get chances like that. I want to do something with my education.

Shamini’s quote points to the paradox that even when they surpass the barriers to education discussed in Chapter 3, WWD encounter a new set of obstacles that prevent their inclusion and advancement. If they were able to finish their education they graduated to new aspects of physical inaccessibility; negative attitudes; and institutionalized discrimination. From this perspective, it appears the current system was built to keep WWD on the periphery of society. The institutional discrimination inherent in a medical exam that determines eligibility for government employment is also mirrored in one required to get a driver’s license. Women from all over the country desired to get a license but were overburdened with the institutional barriers to getting one.
Disability-based License Discrimination

In addition to noting ways men receive different employment opportunities, discussed in Chapters 3 and 5, Jaana was also frustrated by gender differences in relation to earning a driver’s license: “…the government gives men licenses for autos and cars. Men can drive autos, but we can’t. We are not given licenses although disabled men get them. Our community can’t accept women driving.”* The costs of hiring an auto make it much less likely PWD can leave their homes. Like Jaana, many women brought up the systematic discrimination involved in trying to get their driver’s license. Vaishnavi, one of two women with a license, detailed her experience navigating the system. She heard passing the medical exam was going to be difficult, so she and a group of other PWD requested the help of ECBO to facilitate getting their medical clearances and then their licenses. After receiving the medical reports, they applied for the license:

I am the only one to ride my own vehicle. The others could not ride mine because they had disability in their legs, so they got the three-wheeler license. […] we all went together, 12 of us, and I am the only one to get a motorcycle license. Two other people got a license to drive an auto because they also had their own vehicles.*

Her group enlisted the help of the CBR program and still only three out of twelve who paid for their application were successful. It is likely without ECBO’s assistance the number of licensures would have been fewer. Many women described their ability to drive a scooter; however, Vaishnavi was the only woman with resources to purchase and modify the brake operating system on her vehicle prior to the driving exam. Jaana, mentioned earlier, noted the bias in her community and compared the number of men with disabilities operating vehicles and the women she knew who had unsuccessfully applied for a license. An area where inaccessible transportation notably impacted the women’s well-being was in accessing healthcare, the next and final section in this chapter.
Inaccessible Path to Universal Health Services

There are multiple overlapping social aspects of well-being. This chapter addresses several social determinants of health, such as access to housing, clean water, and nutrition. The third theme focused on limitations of rehabilitative technologies and questioned the role they played in increasing women’s health and mobility. The previous theme addressed systematic discrimination in the form of employment and driving licensure, two areas that impacted the women’s overall well-being and inclusion. This section details systematic barriers preventing WWD from accessing health care. Everyone at some point requires access to health care and medical services and WWD are no different. Accessing medical services can be a challenge for everyone, e.g., financial burdens or long queues. This section describes shared barriers and specific obstacles WWD mentioned encountering in the health care arena.

A section on health services is important, especially as none of the CBR programs in this research directly assisted the women interviewed to access medical care. This is a glaring gap—over half of the interviewees mentioned coping with secondary ailments and the need for improved access to health care. Furthermore, all women will need access to health care over the course of their lives whether or not it is related to a disability. Some of the most commonly reported ailments were vision difficulties, diabetes, stomach pains, headaches, leg pains, seizures, fainting and fatigue, infections, cataracts, incontinence, numbness, lack of appetite, physical imbalance, light sensitivity, asthma, back pain, allergies to prostheses, and complications from surgery. Physical imbalance was common for many women and some noted the unpaved, rocky, and uneven conditions of the roads in their villages made it very difficult to walk outside.
The vast majority of the country does not have sidewalks, so a pedestrian’s decision of where to walk is always a calculated one. Variables to factor in may include: time of day and amounts of traffic; width of the road; weather conditions; amount and quality of the walking space on either side of the road, e.g., the grade of the shoulders; and anticipation of aggressively protective dogs, just to name a few. Geetha recently fell and injured her arm while walking along an uneven road in the city. We met at the NRC after she visited the center for physical rehabilitation exercises for that shoulder injury. She and her daughter, Tharany, were introduced earlier. Their large family lives in a prominent fishing area where they must contend with additional environmental hazards. Geetha noted her community asked for the fishermen to improve their practices but they continue to dry and clean their nets in the neighborhood. This setting on the street creates dust that contaminates the air and contributes to breathing issues for those who walk outside. They have called the police but feel “no one cares about our problems.” Geetha noted the educated, those who understand the local issues, do not stay long and end up leaving the area, making it harder to change society. The road conditions, and Geetha’s feelings about her village, reference ways geography and class intersect to impact mobility.

Difficulty accessing public transportation was a theme often discussed. In Chapter 3 transportation was identified as a major barrier to education. In addition to issues related to riding the bus and the expensive cost of hiring an auto, women noted physical barriers related to accessing schools, banks, and hospitals. All barriers are multi-faceted and important, and the focus of this section is on the inaccessibility of medical care that were conveyed in our conversations. The need for disability priority lines was mentioned as a solution in relation to the difficulty of standing in line both at banks and hospitals.
Long travel distances and considerable waiting times at hospitals are widespread issues across the country. After experiencing extensive injuries during the war and battling a significant infection in an army camp, Thivya, in the east, traveled by bus at 4:30 in the morning for weekly physiotherapy appointments at the hospital. If she knew someone working at the hospital that day they would take her appointment card and get her a number in line so she would not have to wait so long. Otherwise, an appointment might take all day, at least 12 hours with travel and wait time. If Thivya arrived at the hospital at seven in the morning, she expected to be seen around three in the afternoon. She made some progress in therapy but now no longer traveled to the hospital regularly. When she does attend, her local bus conductors support her to make sure she gets a seat. Thivya’s challenging experiences with healthcare access were not unique. Based on conversations, long waiting lines at government hospitals were not the exception but the rule. Even though the state theoretically provides universal health care, when it takes all day and requires a disregard of family and work obligations, what does this mean in terms of realizing the health of WWD?

Nayana, the leader of CCO, had polio from a young age and used a wheelchair for mobility. As a leader, she encouraged women to speak up and fight when they encountered areas of inaccessibility:

I don’t feel any difference. I have not gotten bullied or cornered. Now with my disability, unlike other women, I’m more active and I was always like that […] I have not felt like I’m missing something. Yes, it is kind of a loss, but I have not felt it to my heart. […] From society I have not had a lot of direct discrimination. But whenever there has been any discrimination I have always fought back. Like for example, if I go to an office and there are only stairs and it is not wheelchair accessible, I would inquire with officers and ask them. “why discriminate and not have a ramp? Funds are distributed for everyone, why isn’t there a ramp?” Other than challenging the differentiation of treatment. I don’t feel affected by it.
Nayana’s inclination to confront unjust treatment was unique. Many women I spoke with were not shy but may be considered reserved. In our conversations, Nayana also came across as reserved; however, in this excerpt she describes how she asserts herself and “fights back.” At the end of our interview she asked how I “found” the women I spoke with for my research and I told her they were strong. She replied, “that’s the way, a lot of Sri Lankan women are strong.” Nayana’s experience addressing physical inaccessibility is relevant to the recent Supreme Court decision that found the inaccessibility of public buildings, including hospitals, was a violation of Sri Lankan’s constitutional human rights. The decision supports action on part of the state to implement and enforce existing laws and regulations related to the physical accessibility of public places. While only a recent decision to address pervasive problems, it is progress.

Bimali, in her early forties, was quoted at the beginning of this chapter related to her housing instability. She was battling an infection in her legs and her nearest government hospital was around four hours away. She said she goes there by bus with great difficulty. Her medications are given free by the hospital but it is very difficult for her to get them since it is so far from her home. Bimali noted the hospital’s treatments were ineffective in removing the infection in her legs, and she switched to Ayurvedic medicine because of distance and costs associated with hospital treatment. She was one of three women who took out loans to pay for medical expenses. For her next visit, in the near future, she would have to borrow a small loan from a neighbor or a friend for transportation costs to the hospital. The hospital near her has fewer treatments available and she knew based on the progression of her infection they would refer her to the larger even more distant hospital if she went in locally for treatment. When asked if the clinic could provide a ride to the hospital, Bimali replied:

I have been to the hospital due to it getting infected. I get it cleaned, operated on, and dressed. It gets a bit better and then again goes bad. […] For the last six months I haven’t
gone and now only I’m going. […] Mostly I go when the pain is unbearable. […] There is a small hospital close by, it’s not so good. Not developed. […] For a developed hospital you have to go to (town name) but even there they will send me to the farther main one. […] in the ambulance they send me […] Every day it’s hard to do that. They won’t send only one person like that, unless you had an immediate operation or a wound/emergency […] Tomorrow I don’t know what they will do. I have to go to see.

Many women reiterated Bimali’s experience with inadequate access to care, both economically and geographically. Her lack of finances and the long distance from her home to the hospital were the main reasons she waited so long to get treatment, and it was evident her legs were paining her during the interview. Another woman associated with SRC in her late fifties, also cited transportation expenses as a major barrier to accessing the treatment she needed after her aneurism. Her family’s Samurdhi, a monthly social welfare program for low-income families, had been discontinued for her family and many other families in her area.

She described the financial burden of travel after her surgery, a time when she would have to go to the hospital twice a month. The clinics themselves did not cost money but travel expenses to get to the clinic were too much. She was unable to travel by herself, doubling the transportation costs and requiring her husband to miss a day’s work. Her doctors wanted to schedule physical rehabilitation sessions for her to increase functioning, but that required hiring and paying an auto for the whole day because of their remote location and the necessity for the driver to wait at the hospital until her appointment was completed. She declined the services because her family did not have enough money to transport her from their home to the hospital.

Another woman we met through the SRC also referenced costs when I asked why she stopped attending the free diabetes clinics. She wanted to improve her vision but noted the prohibitive expense of travel related to accessing optometrist services and getting eyeglasses. It would take 90 minutes to travel from her rural home to the eye clinic, an expense of about Rs.2,000. Instead her husband, who was only able to find work occasionally, assumed the
responsibility of traveling to the hospital to get her medications. Many, like her, women hoped to
correct their vision. One noted her travel time to get spectacles would be over an hour, not to
mention the prohibitive cost of the glasses, Rs.5,000, an amount more than the monthly income
poverty line.

Chamari, who balanced the finances of both wanting to build a home for her children and
treat her husband’s illness, spoke of significant financial struggles throughout her interview. In
one instance, she detailed how a local government representative failed to secure a small daily
stipend for her family when her husband was in the hospital for three months. The insurance
program, run through the social welfare department, was to provide Rs.100-200 per day
allowance to support families when a primary earner is hospitalized. Chamari spoke with a
district representative of the program and was told her family was entitled to the money;
however, they were left with nothing after the local representative at the village level failed to
follow through. Told by others she could seek out the funds, she said she would not complain
because the representative who didn’t help her “will feel a big pain when she remembers.”

Data show access to medical care in general is difficult in rural areas, for WWD these
difficulties are magnified. Care from this context is physically, geographically, and financially
difficult to access. Women experienced significant hardships and struggles but also detailed their
resilience in the face of adversity. Some excerpts in this chapter feature women in the midst of
their battle for a better life and many detail experiences of great sadness. In contrast, others
spoke of feeling triumphant they had overcome the hardest and lowest points in their lives. Many
expressed they found happiness and held feelings of strength that kept them going as providers
for their families and leaders in their communities.
Summary

The disconnect between CBR programming, well-being, and the lived realities of social impacts to women’s health were highlighted in this chapter. Viewing experiences through a critical lens with regard to disability and gender proved important areas of analysis. This data highlighted social features in need of attention related to bodily aspects of health and inaccessibility. The first section detailed the inseparable intersection of gender and care, along with the uncertainty facing many WWD as they age. The second theme, so prevalent in interviews, centered concerns of housing instability and conversations of meeting basic needs. The third major aspect of this chapter highlighted a clear misfit between prosthetic and assistive devices and what women want in order to get the most benefit from these technologies. The final theme is a big one: systematic discrimination and pervasive inaccessibility. Discrimination in the form of ableism is a blanket term that can be applied to most barriers and pitfalls WWD experience. Yet for this chapter and the data presented within, systematic discrimination is also evidenced by inaccessible built environments that serve as a major common denominator that limit the well-being of WWD.

The strengths and successes of women in this research are a testament to their incredible determination. In the midst of their struggles they continued to fight to break cycles of isolation and marginalization that relegate their lives to the periphery of society. They challenge gender norms and expectations, change what it means to be disabled, and persistently advocate for society to just give them a chance. Chapter 5, the next and final findings chapter, elucidates the intersection of gender and mobility further than other chapters. The first section details the cascading impacts of invisibility WWD compete with, socio-cultural experiences of men as the primary resource bearers, and the beginnings of an intersectional social movement.
CHAPTER 5. WOMEN’S MOVEMENTS AND MOBILITY

A concept common in Buddhism in Sri Lanka: the notion that being born a woman is a consequence of sins in previous lifetimes. Traditionally, a common aspiration among women was to be a man in a future birth, for only a man could become Buddha. Accepted ideology in traditional Sri Lanka thus required women to subordinate themselves at all times to the male… (Jayawardena, 1986, pp. 114-115)

Introduction

The Role of Male Guardianship

A lasting influence of colonization and capitalist penetration legitimizes the subordination of women’s status within the family (Jayawardena, 1986). The necessity of a husband to serve as the protector of his wife and family are detailed in Chapter 3. The role of men is expanded upon in this chapter, not only as an expectation of social and material resource through marriage, but as a cultural connection and dependency based on virtue of gender alone (e.g., the role of father, brother, and husband). As discussed in Chapter 2, and in various other moments throughout this dissertation, expectations of male guardianship impacted my fieldwork as well as the women’s mobility in various ways.

Paternalism is institutionalized in the laws. For example, although it appeared many businesses ignored a nation-wide ban on selling alcohol to women in taverns, the practice is still illegal. An amendment to “restore gender neutrality” and lift the 40-year ban in 2018 was rescinded by the president soon after the law’s passing (France-Presse, 2018). I found the cultural expectation of male guardianship especially salient in my attempts to find women to work as interpreters for my research. In the end, I was able to hire two women without fathers who were therefore not obligated to request permission to work with me. This theme was also evident when my roommate and I were asked to leave our apartment because our status as single women living without a man in the house was viewed as a liability. We were told our mere
presence as women tenants negatively reflected upon the reputation of our landlord and his wife. Soon after, I located an apartment for the rest of my fieldwork with a clearly defined lease.

**The Role of Women**

The historical exploitation of Sri Lanka’s labor and agricultural resources by the West did not exclude women. In the colonial era, women of a lower class were “the cheapest source of labour” in agricultural fields, while women from wealthy families were educated and groomed to be obedient Christian wives and mothers (Jayawardena, 1986, p. 8). Globally, the notion of women as the cheapest and most expendable form of labor remains. Within a neoliberal context, women are not only primed to perform multiple roles within society, they are expected to do so as a positive asset, never needing anything. Vimala, the leader of SRC, illustrated this in her quote about women’s status: “If they are independent, as long as you are not a burden, you can do your own things, you know and have children that is. [...] That’s it, then the men are fine.” Her assertion locates a theme related to CBR program efforts for WWD that operate within neoliberal and patriarchal sociocultural contexts maintaining typical gender roles and prioritizing women’s marriageability. Critiquing gender roles does not undermine the current social importance and investment value of marriage, a theme discussed more in-depth in Chapter 4.

A “women headed household” (WHH) is a vaguely defined and contested conceptual term, yet this phenomenon is important to discuss. In the 2000s, Sri Lanka was estimated to have the highest percentage of WHH in their region. One in five families was managed and likely financially supported by a woman, and half of all WHH were led by widows, one out of every ten families nationally (de Silva, 2005). These estimates were collected during the civil war, indicating there may be an underreporting and geographic bias in the sample of women who were counted and those who were not counted. A limitation of de Silva’s work is the omission of
a discussion of ethnicity related to WHH. Research based in Sri Lanka by Ruwanpura and Humphries (2004) critiques the universal standardization of household types. The authors argue against linking the country’s political strife to the incidence of WHH, instead noting WHH in Sri Lanka existed before the civil war and are not “the product of war and turmoil, an aberration that will disappear when peace breaks out” (p. 174).

Sri Lankans live with a multiplicity of intersecting identities shaped by both their current status as well as a complex history of colonization and conflict (Rogers et al., 1998). The prolonged war has complicated women’s roles “within cultural frameworks that enable or disable them” (Rajasingham-Senanayake, 2004, p. 165). Rajasingham-Senanayake’s research provides evidence that war, through the loss of family members and a breakdown of kin structures, carries with it increased personal and group autonomy, essentially forcing women into leadership positions within their households and communities. In locating women’s agency within this context, although sourced from violence, the author problematizes development programs’ perpetuation of trauma by treating women solely as victims (p. 148). Rajasingham-Senanayake argues while women’s movements are often mobilized along ethnic lines, there is transformative potential in their refusals to conform to traditional roles (2004). Consequently, shared experiences of disability across ethnic lines have the potential to facilitate relationships and form powerful alliances (Kandsamy et al., 2017b; Samararatne & Soldatic, 2015).

In this chapter, mobility is considered not only in terms of personal and physical spaces but also social spaces. Specific ways women are expected to individually overcome structural barriers are identified and problematized with a goal of questioning neoliberal expectations that all individuals should be able to do everything on their own. A neoliberal individualized focus comes at the expense of potentially powerful large-scale social development programs. Findings
demonstrate ways women navigate, subvert, and thrive outside of patriarchal control. They work hard to overcome social barriers and discuss ways they plan to confront future challenges.

**Findings**

**Theme 1: Cascading Impacts of Invisibility**

The third CBR organization that agreed to host my research, the Southern Rehabilitation Center (SRC), was centrally located on a highway about two kilometers from the nearest town. Like multiple CBR programs I learned about, SRC was in a transition period. Many programs were experiencing a scarcity of funding. Monetary assistance for community-based programs has been on the decline for years. At the time of my fieldwork, it had been over a decade since the 2004 Boxing Day tsunami; the war, and the status of a nation in humanitarian crisis, ended in 2009; and the country’s GNI was quickly on the rise from a LMIC to a UMIC.

The present research found Sri Lanka’s decrease in development priority status overlapping with a changing of the guard. Aging Sri Lankans who worked for several decades within their communities led many of the CBR programs I encountered. Their upcoming retirements are interesting to note because while the mission of the programs will likely remain constant on paper, in actuality, it is the leader who decides how the program operates within the community. For example, they determine what types of grants and trainings staff will apply for, prioritize particular aspects of staff hiring and development, and allocate resources on behalf of certain target beneficiaries. Collecting this type of data is one of the many strengths of using ethnographic research methods that allowed me to view how things were socially organized on the ground. This perspective is especially important in multi-sectorial intervention settings where there may be misalignments, both beneficial and not, involved with professional implementation of policy and best practice.
As noted, SRC appeared to be in a period of transition. The leaders of the NRC, NVCC, and CCO were also reaching a life stage close to retirement. SRC was the only site with two leadership interviews. I was able to interview the founder of the organization, Vimala, as well as the director, Dinesh. Through Vimala, I learned about the original mission of the program, and through Dinesh their current and future work in the community. As discussed in Chapter 3, none of the interviewees mentioned receiving any type of education service or benefit, although early education and health screenings were foundational programs of SRC.

The organization began with a mission to help children with various types of disabilities through early identification and education. When Vimala began her work in the community there were no statistics available. She said, “I went and wrote out handbills myself and went and stuck them in public places with my address on it. Within two weeks I had 45 letters and I started only with children.” The response was so overwhelming in such a short time that Vimala quickly went and removed the handbills so she could cope with helping the first group of children. She said at that time the CBR model was to go inside the home, but “then I realized you know if we do that, still they are segregated” so she started a preschool in the community. This way:

They are seen. They are noticed. I mean buses didn’t stop for them. We had to do some awareness with the bus drivers […] from zero, from zero really, we had to change the mindset of the community. First the families, then the community. The families just did not, the mothers never played with these children. They didn’t know how to handle them. So even that had to be taught. […] They used to always think it is useless investing in these children […] even nutrition you know in the poor area. […] Today it’s an entirely different attitude. They love their disabled children more. […] Then the other experience, one of the earliest, is that we found the fathers just leave the children and the mother and they go. They leave the family because they blame it on the mothers that these children are like this. […] All that. We brought about a huge change. The community took us years […] Actually to tell you the honest truth if I knew that the need was so much, I would have got cold feet and just dropped it. But it just grew, grew on me, grew on us. When you find something that is necessary, we do it.
SRC’s work in the community had grown from early intervention and primary care to large-scale community outreach and center-based programs. The organization’s scope of interventions for WWD were wide-reaching and took the form of housing and business grants, physical rehabilitation, assistive devices, and livelihood trainings. For recruitment, three SRC FOs, all women, took us out in the field to meet with 15 WWD across three large districts. Like many of the leaders and women I interviewed, Vimala noted progress had been made and attitudes have shifted around disability compared to “the earlier days.” She clearly described CBR’s intervention model as one with a mission of increasing disability visibility and educating the community (e.g., changing the mindset of parents and bus drivers). Themes discussed throughout this research touch on experiences of WWDs as young girls, and the important role families and communities have in pushing them to learn. The next section elaborates on the persistent lack of visibility WWD experience. It locates pervasive social marginalization within common experiences of imposed guardianship through family and community processes.

**Hidden from Childhood: “Don’t Go Outside.”**

A major theme revealed in interviews was the expectation to stay hidden, although some women spoke of the role CBR programs and parents had in changing this. Quotes included in this section are specifically related to children with disabilities being kept inside their homes, sometimes the women themselves experienced this and other times they advocated on behalf of those who were sheltered by other families. For example, sometimes they told stories of neighbors or other people in the village with disabilities. One woman told us of a teenager living close by whose parent’s refused to let him out of the house despite SRC’s attempts. Lakmini, single and living at home with her parents, said she was kept mostly inside until she was almost thirty. At that time seven years ago, a CBR field officer (FO) came to her house and requested
her family allow her to go to temple by herself. She explained, “After the FO has come and spoken to them then they thought that they should let me out and socialize. If not, I have not been let out.”

In our conversation, Vimala noted many parents of women and girls with disabilities were too afraid of the community to allow their daughters to leave the house. A few women noted sexual harassment in public was a major issue. Vimala said families keep them inside even when community programs offer school, work, or other training opportunities. Her program advocated for increased visibility and educated parents about the need to let their daughters out.

When I asked about why parents continue to shelter their children, she noted:

They feel threatened. I mean especially now even these young girls, girls with down syndrome and all I would love to bring them to work but the parents are afraid […] they are very protected […] they are very loving people, so they, they get attracted when young boys and so on. I mean we have had some cases where the mothers have asked us whether we can give them birth control pills […] I said, “what is this, you are encouraging this to happen rather than discouraging? You have to take the responsibility, do not leave your child alone and go.”

The above quote touches on multiple overlapping areas of oppression related to gender, sexuality, class, geography, and intellectual disability. This dissertation does not explore the majority of themes overlapping in this quote, but it calls for a more nuanced and culturally specific examination of factors involved with the guardianship of women. Tharany was almost finished with university in the north. She used a wheelchair and only went out with assistance from a family member. She noted harassment was an issue for all women, and that in the past she felt helpless, especially during the war with no way to evade missiles quickly. Now, she felt safe. She had numerous avenues for support and guardianship when she needed to leave the house, including from her father, husband, and many brothers.
Hiruni, from a central region, explained how her family made her stay at home until they learned of a residential CBR program for WWD. Her father accompanied her to visit the program and gave her permission to join when she was 22 years old. Hiruni described working at CCO as a “light in her dark life”:*

I was inside my house, like a prison, and then I got freedom. My teachers here, they always encourage me, they are the reason I am where I am today. Before, I had never done grocery shopping, or worked for an office […] I suffered a lot, mentally, when I was back home and was very unhappy […] My family wouldn’t let me go anywhere because I am disabled. […] I was always inside, and my parents pitied me.*

Hiruni’s experience of being sheltered inside her home through intense family protection was common. Her quote of not being allowed to do anything and not being pushed by her family to learn was echoed by many women and is discussed more in Chapter 3. All of the women expressed a willingness and desire to be pushed and to be given a chance to succeed. Instead, as Hiruni’s words describe, families often keep children with disabilities hidden inside. There are rich complexities evident related to reasons for sheltering them that involve socio-cultural fears related to protecting family reputation or the well-being of PWD. One example was included in a story Arunadhan (NVCC) told about an interaction he had with a highly educated coworker:

A professor at my university said, “I want to send my daughter to your community program. Last night, when I went home, she took a big stick and hit me and asked me to take her to NVCC.” I said, “Why?” He said, “she can’t hear.” Every day he used to drop her at NVCC and she worked. Very good, intelligent girl, and she started learning to make various things and that. Twenty-four years-old and she had never gone to school. A professor’s daughter! The only thing is, he had two daughters. “I keep her at home and therefore nobody knows because if they know that I have a deaf daughter, the other two girls will not be able to get married.” She’s a family of deaf, therefore the bridegrooms will think that their children will also be deaf therefore they will not get married. This is the reason why people keep them in. That girl was never sent to school.

Arunadhan’s account of his interaction with his coworker touches on multiple messages I heard during my observations about misunderstandings and stigma related to disability, womanhood, and reproduction. His story also brings family status into the fold, noting that a
sister’s level of marriageability may be impacted by having a sister with a disability.

Connections between marriageability, disability, and siblings, speak to the power given to men and men’s families in determining a marriage match. Arunadhan’s quote notes the prevalence of WWD being hidden as well as the neglect WWD encounter related to education. At the end of my fieldwork with NVCC, I had lunch with Arunadhan. While eating, we talked about his work in the community. He said some people in the area believe he is going against the will of God when he helps WWD because, “they are being punished in this life for sins of a past life. They deserve to live a disabled life.” When I asked how he managed these negative attitudes he replied, “I tell them, God put me here too, and to not help would be against his wishes.”

Detailed throughout this dissertation, WWD are confronted with multiple societal barriers. They combat guardianship to get freedom from their homes, and strive to find love while battling stigma from society. Many noted they felt supported by their families, but a few shared intimate feelings of sadness because they felt they were treated differently compared to their classmates or siblings. One woman, in her late twenties living with her parents, shared, “Now, personally, I’m not loved as much as my sister in my house. That’s based personally on what I feel […] the love and attention I get from my family is less.” Kumari also spoke of being sad when her parents would push her older sister to succeed in school but not her. She recalled hiding when her family had visitors because they did not want to show her disability. Jayanthi, in her late fifties, also framed not feeling pushed to excel in school in relation to her disability, poverty, and birth order:

No one pushed from my family; nobody was there to direct me, motivate me. They didn’t pay a lot of attention to me because I am disabled. I am the eldest and had to take care of my siblings. My parents were farmers, so nobody was home to take care of them. I cooked, fed, showered, held, and took care of them.* (Jayanthi)
Even at home, they thought there is no point of me studying because I have to stay at home since I’m disabled. It was out of my interest that I studied. Nobody pushed me to go to school. Sometimes I would go like two to three days. My elder sister did science for A-Levels. She couldn’t stay at home like me. They would yell at her to go to school but not for me. (Kumari)

Kumari’s quote, following Jayanthi’s, identifies shared struggles related to learning experiences in childhood. These experiences led to cycles of social and financial instability, specifically long-term impacts of isolation and neglect related to education. Data presented in this section revealed cascading experiences of isolation and highlight rampant stigma preventing WWD from experiencing full visibility in society. The women quoted in this section shared memories of being hidden solely based on being a child with a physical difference. These experiences of constricted social opportunities from a very early age are qualitatively different from those in the next section that details women’s experiences of mobility in relation to war.

*War and Limited Mobility: “We Had to Pass the Army Camp.”*

Many women stopped going to school because of the war. A few who felt comfortable sharing their experiences are quoted here. As mentioned in Chapter 2, only two out of twenty Tamil interviews have been directly translated using the audio recordings. The lack of translation is especially pronounced in sections that relate to war and ways war impacted the women’s lives across particular domains. Tamil women’s experiences are conveyed throughout the dissertation, but they are often paraphrased by the interpreter and are therefore less thorough and direct. The process of directly translating those audio files was slowed due to my limited number of Sri Lankan Tamil contacts, and the heightened need to protect anonymity due to their mentions of the conflict. Future phases of this work will entail locating research assistants to work on Tamil translations for more nuanced data.
The civil war lasted over three decades and experiences of war were woven throughout the interviews. Ten Tamil women and one Sinhala woman said war was the main reason they discontinued their education. Bimali, introduced earlier, experienced unstable housing and an infection in her legs. She only studied until Grade 5, age 10, because it was so difficult to study during the war when her school was closed (refer to Table 2 for a description of education levels). Bimali said, “sometimes three, four, five months it was closed because of the war. After that I got fed up and stopped.” Others were unable to do well on exams due to the stress of poverty combined with the war. Tabitha, now in her late forties, lost her family when she was three years old. The teachers at her boarding school were supportive, but war required that she leave the area. Soon after, she was married, but her husband left her when she was a few months pregnant. Experiencing multiple hardships, Tabitha shared what happened when given the option to join “the group.” The term “the group” is used in this context to refer to several militant opposition groups that formed during the long civil war.

I passed my O-Level exams but I couldn’t stay there because the ethnic war commenced. I finished my studies and got married, but soon after we separated. I was alone and I had a baby. I struggled alone to provide for our daily needs. […] Some people said to join with “the group.” They advised me, “if you go with the group and if you take care of the kids, the group might support you in looking after your kid.” A relation got to know about this news, and she informed the INGO people, “my girl is in the outside so support me to take her back.”

Tabitha detailed struggles she went through to support her child as a single parent, almost to the point of joining with a militant group fighting in the war. Her quote underscores a lack of social protections that arguably still exist for WWD, especially those who are single parents. Tabitha’s story of being physically rescued from a war zone by a kin network highlights both vulnerabilities and strengths, and underscores the lasting impact of kin networks. Vaishnavi, a young widowed single mother introduced earlier, also spoke of war’s impact on her mobility.
She was scared about what would happen to her when she walked by the army camp on her way to school. In Grade 10, Thivya was on her way to her tuition class when she decided to join “the group.” Later in her interview, when I asked if she knew PWD when she was young, she shared:

At the time I didn’t know about disabled people at school, but I knew many people who didn’t have fathers. I was hurt because my father was kidnapped when I was five years old. At that time, my mother was pregnant with my younger brother. So, I missed my father a lot and others persuaded me on the particular track so I had to do something. They took my father, so I decided to join the group.*

Many interviewees lost parents and siblings when they were young. These losses led to emotional and economic struggles within families. Kumari, said, “My father was doing everything. And after he died it became difficult financially. So, I stopped school.” War created a fearful environment and disrupted the social fabric in many women’s lives, like Thivya, who became disabled and lost male relatives in the civil war. Women in this research often spoke of heavy social and emotional impacts at the loss of their fathers, husbands, and brothers. It is difficult to fully comprehend the short and long-term impacts that accompany decades of violence, including the ways civil war influenced the kin networks of WWD. The loss of any family member is difficult, and the impact of losing male relatives in a patriarchal system is pronounced within the context of examining gender and gender roles. The next theme outlines data related to various socio-cultural roles men hold, especially as they intersect and modify the freedom of mobility and opportunities available to WWD.

**Theme 2: Men as the Bearers of Resources**

I prompted interviewees by asking if they felt there was a difference between men and women in Sri Lanka. Sometimes the question was framed in terms of the differences between “men with disabilities” and “women with disabilities” and at other times it was more of a general question. The question would often have to be repeated because it was seemingly strange. In a
very honest moment, one woman said she could not answer and “if I wanted to know what it was like to be a man with a disability, I would need to go ask one.” Eight women answered directly, saying, “if disabled, it’s the same,” others shared they felt men with disabilities encountered problems but still enjoyed more opportunities to get jobs and get married compared to women. Lakmini, quoted earlier about how her teachers should have helped her more in school, lived with 10 other family members in her older brother’s small house. She giggled while answering the question, “What’s the difference between being a woman and being a man in Sri Lanka?”

I would mostly like being a man. I mean, the difference is, when you’re a woman you have to take all the household pressure, have to do laundry, have to cook. The woman has to do all the household work. For a man it’s not like that, they just have to go to work, come back home, take a shower, and just sit.

Lakmini’s comments come with the reality of living with her older brother who provided the only income for a household of 10. His wife, children, mother, and three disabled siblings all lived with him. Lakmini said they all live happily there; however, her joke addressed stark gendered differences within the home, including struggles to maintain household chores in a small space with such a large family. The next section expands on this theme and uses examples women gave of their emulation of men based on more masculine roles they had performed.

_I Provided for My Family “Like a Man”_

One in four women were the heads of their house (WHH) within this sample. This figure is more than de Silva’s (2005) estimate of one in five (p. 16). Some women did not discuss their parents; however, 10 mentioned through the course of our conversation that their fathers died when they were young, and two had lost both parents at very young ages. The impact of losing parents is powerful across all cultures and contexts. Losing male relatives denotes that women in the family must assume the financial struggles and economic burdens that their fathers, brothers, and husbands had once carried. In line with reported statistics, five women in the sample were
widows, four Tamil women and one Sinhala woman. Some had lost brothers due to the war.

Lalitha was contacted through CCO. When we asked her about living as a woman in Sri Lanka, she said she did not really need to think much about it. Instead she underscored the importance of how poverty has impacted her life. She said poverty in her country is not adequately dealt with:

   Honestly, I have had a rough time growing up in poverty, but with my determination and with my husband passing away after giving me four children, I still educated all of them. And I was like or equal to a man, and I feel at times not even a man could have done what I did.

Lalitha was injured on a bicycle in the 1980s, and raised all of her children to adulthood as a single mother. She struggled then, and at the time of the interview, was working to expand her small-business storefront in her home so she would not “be a financial burden to her children.” Her quote notes an awareness, as well as an opposition, toward gendered expectations of working hard and raising a family. Along similar gender lines, when asked if she was treated differently, Rani mentioned working on rural farms prior to her motorcycle accident. She noted that some women could not work as hard as men, but she was a strong woman. She told stories of using buffalos to plow fields and of her bravery during wartime when she heard a rumor about conflict in another village. Rani left her village on her bicycle to see what was “really” happening. After the incident, the policemen praised her efforts and told her, “you are brave like a man,” questioning the men bystanders, “you, look at this woman who is brave and strong!”

When prompted, “are women treated differently than men in Sri Lanka?” Bimali shared that prior to her injury her neighbors saw her “as strong as a man.” Earlier, she did not have any problems and worked on par with a man. Her village knew she was strong and used to say she worked like a “kolla,” or young man. She expressed sadness that everyone in her village now felt sorry for her because of her family issues and her battle with reoccurring infections after her accident. Although the few excerpts above display gendered expectations of men as physically
strong and necessary to support their families, they also underscore roles many women filled in working both within and outside of the home to support their families.

**Male Guardianship and Housing**

Bimali, quoted earlier, was dealing with a significant infection in her legs when we interviewed her. Details of how rurality and poverty impacted her ability to receive medical treatment are discussed in Chapter 4. Bimali attributed her precarious housing situation to the failure of her father to mediate her conflict with her stepmother. Years prior, Bimali flew home from abroad just to argue for an approval with the local government to build her father’s house. At the time of our interview, her major concern was not being welcome in the home she built and her father was too ill to advocate for housing on her behalf:

I have requested for aid, and the government is saying to join the program and get in line to be eligible for a piece of land. But right now, even today I don’t have a proper place and I might be asked to leave, do you understand? Suddenly if I’m asked to leave, what do I do? I’m a woman! Am I to live on the main road? Am I to sleep in a retirement home?

Bimali expressed deep frustration at her treatment in society and said she was going to bring her issues to the human rights department. She knew her rights, communicated them, and navigated government systems, yet still struggled with housing instability and a persistent infection in her legs while residing in a very rural location. Her reference to her father as unable to resolve family issues underscores the significant role men have related to women’s social and housing status. Layered on top of that were her struggles within a social system that lacks avenues for recourse, especially for women.

Aspects of Bimali’s and Thivy’s struggles in accessing health services are elaborated more in Chapter 4’s discussion of social factors impacting health. In addition to illness, Thivy dealt with military surveillance based on her involvement with the war. She shared multiple
areas of difficulty related to living as a WWD. She faced discrimination in trying to apply for bank loans; secure housing; combat excessive military surveillance; and address the spread of gender-based rumors in her community. The bank denied Thivya’s request for a loan and told her “because you are disabled, you can’t get a loan, and you’re also not yet married.” She expressed frustration at being blocked so discriminately when just trying to “get her bread and butter herself.” When asked about the framed certificate hanging on her wall, she moved a picture that covered up the name of her father who was kidnapped during the war. His name was written in the place of where a husband’s name would go:

> They said earlier unmarried people were unable to receive the houses, but the divisional secretary said because I am disabled and we lost my father, that we are qualified. Then a worker of an NGO requested I transfer money for the housing project, a bribe. So, I just recorded the conversation, and I brought it to their superior officer and they said, “it’s okay we’ll take action.” […] I am well qualified, but they are just arguing with me that the only thing I don’t have is that I am an unmarried, “so you are not married, we are unable to give.” But I was willing to argue with them because I have these qualities. I am qualified to get a house. Some other people provided money, they gave money to that particular officer, but I didn’t want to. It was a big crisis.*

Institutional discrimination based on marital status, although successfully defeated in Thivya’s case, is indicative of many barriers facing women in their efforts to secure housing and provide for their families. Thivya detailed her struggles against discrimination and the corruption of those in positions of power. Her efforts fighting against the system paid off and she was allowed to build a home as a single woman. This ingrained paternalism was also evident for women at NVCC who while they said they could move freely and “come and go as they wish” were still required to follow a check-out policy where they would call from their phone or their father’s phone to confirm with the director they made it to their destination. The casual reference to the requirement a male relative confirm their whereabouts signaled a deep-rooted social norm
of male guardianship. The next section addresses issues that arise when women are viewed as nonconforming in relation to gendered expectations.

**Male Guardianship and Gossip**

Many women expressed ways they personally dealt with and confronted gender and disability related bias. These examples were mostly in relation to community reactions to their economic and social participation as single women outside of the home. Pushpa mentioned this when I asked about the most significant problem for WWD in Sri Lanka. She said there are so many: challenges with getting a good job, a lack of formal education qualifications, and inaccessible public transportation. However, the most salient concern for Pushpa related to gossip. She experienced increased gossip because her husband was away for two months receiving medical treatment. To curtail harmful rumors when he was away, she did not stay at their home alone and instead slept at her mother-in-law’s house in the same neighborhood:

> This is a problem impacting not only disabled women. […] The big issue is, in our culture, in our society, we have, for instance, if I stay here alone tonight, and if someone comes and knocks on the door, the neighbors will start gossiping. They’ll say like, “oh they do like this” for instance. People like starting rumors.*

The indication that gossip is a major issue, especially according to the Tamil women interviewed, may be linked to the significant disruption of their communities and kin networks during and after the war. Many Tamil women were displaced by war. While some were able to return to their ancestral lands others were resettled to different areas. The ways women’s relationships within their communities evolve over time in post-war contexts should be studied further (Rajasingham-Senanayake, 2004; Thiranagama, 2011), as should aspects of women’s agency while navigating expectations of male guardianship, employment, and the role of “good girls” (Lynch, 1999). Thivya, in her thirties, also said she and other WWD experienced gossip. For her, experiences of gossip were connected to government harassment and surveillance:
They always come for the inquiry. Last time they came, I was bathing. They usually wait at the gate. Sometimes I’m eating, they don’t care, they wait. It makes me so angry, stressed, and irritated. Sometimes, they come after dark. It’s really bad for me. One day, they came and they dug all our lands. They said they received a complaint that I was selling liquor bottles illegally. I just argued with them. It’s always happening. One day I just very harshly spoke with them. It’s so much of an irritation. Then neighbors ask me, “do you love the CID people?” or “Do you have a love affair with them?” Because they always come here. I spoke with them very harshly, “I’m going to write a letter. Because of your torture, I’m going to commit suicide.” I was so stressed I thought to commit suicide. But then I gave a letter to the IOM and also the human rights committee too. This is a big, big, problem for me. Still they inquire. They don’t come to my home anymore, but if I go somewhere else, they’ll come and ask, “what type of meeting did you do? Where are you going?” These types of questions, since the day I arrived home.*

War is woven throughout the themes of this dissertation. Some women appeared slightly uncomfortable when speaking about disability or wartime; others appeared to use our interview as a platform to share. One woman had completed over a dozen interviews, yet others had not been approached for an interview. Tabitha, introduced earlier, had not spoken with anyone like me about her story. When she was three, she became an orphan due to a tragic event in which she also lost her leg. She married at 19 years old, became pregnant, and soon after her husband left her and her child. When I asked Tabitha about her biggest problems, she spoke about maintaining her reputation as a single woman:

If you take my whole life, my whole life has been a challenge, from the beginning, from my younger age. It has been very challenging. I lost my whole family, no husband and everything. So, it’s been challenging for me. I expected love from a husband, but it was different and strange. Then, I had a strong idea I should overcome and face every challenge. So, I bravely faced everything. I don’t want to attract any problems. Some people want to make problems, create problems. They want to get me involved with their issues. These things have affected me as a lonely woman. I don’t want to trouble with these types of things, so I’m trying to escape the rumors. I have respect.*

Ramesh (leader, ECBO) also noted experiences of gender-based gossip and added war-associated stigma when asked about gender differences:

Say I am a woman who came from an army rehabilitation camp and I have a job. I’m also stamped as an abused person. So, I don’t have any chance to marry or get into society. But for the men, there aren’t any problems like this.
Aspects of community in relation to gender, mobility, and war were highlighted in this section. Findings detail nuances related to barriers limiting women’s roles in society and how personal struggles continue to alter social and physical mobility. In spite of multiple significant obstacles, women protested, fought, and challenged dominant gender norms to reposition themselves within areas of society often reserved for (or alongside) men. The last section briefly introduces the fifth field site and then transitions to the last theme discussed in this dissertation: the beginnings of social movements determined by WWD.

**Theme 3: Framings of a Social Movement**

Ten women were interviewed from the final CBR field site. I was excited the Eastern Community-based Organization (ECBO) was interested in hosting my research as the region was previously off-limits for Fulbright funded research projects. This geographic restriction had likely been lifted along with a 2015 transition of power within the government. I arrived in 2016, just after the policy changed and was free to conduct research in any region of the country. I spent two months living in the east. This area, like much of the country, is rich with natural beauty. Drivers here preferred to confront oncoming traffic before disturbing a cow standing still in the middle of a busy street. It is a region marked by war, natural disasters, and resilient people.

My primary contact with ECBO, Ramesh, was very engaged in assisting my research. He made himself available for interviews, helped with logistics, and invited me to an outreach activity. During our meeting, Ramesh drew organizational diagrams to help me understand the structure of the CBR program as well as the network of relevant government sectors (e.g., Ministry of Social Services and Ministry of Health). At that meeting, he noted the support of the local government in relation to sponsoring a disability awareness day. His passion and enthusiasm for
community activism was reciprocated by the WWD he worked with, and my interviews with the participants of ECBO proved to be a wonderful way to wrap up fieldwork.

**Building Camaraderie with WWD**

This section details experiences of camaraderie related to gender and disability. These perspectives indicate the potential to build on a social movement. As noted in previous sections, Kumari and Hiruni both worked at CCO and each spoke of being “kept hidden from society” because of their disabilities. As a result, Kumari said she used to avoid interacting with others with disabilities:

> They think negatively about disabled people, because they assume that they cannot do anything or go forward. […] I would hide in the house if we have visitors since my family doesn’t like to show that I’m disabled, therefore, this may have had an impact on me associating with such people. […] But after I came here, I realized that we are all one and then I changed. Before, I would try to avoid disabled people but now if I see someone like that I go and talk to them.

Like Kumari, many women noted they gained confidence from interacting with other WWD. As mentioned, we interviewed Asoka at her roadside shop located along a busy highway. She shared experiences of leaving her abusive husband and struggling to provide for her son. Her story of growing up deaf and ending schooling early because her mother was too afraid to allow her to ride the bus alone are detailed in Chapter 3. At the end of our interview when I asked if she rides the bus, she replied:

> Yes, I go in the bus. Even to Colombo I can go alone in the bus. When I was working in CCO I got experience and learned to take on any challenge. Having that strength is what keeps me and my child alive. Before, I was afraid even to talk to anyone. Now, I’m not afraid. I can go anywhere, and I can do anything. Now the stuff for this market I bring it alone. Everything I do alone. There is no one (laughing).

Many women said they were motivated to be strong for their children. Some noted they gained strength and confidence through CBR programs and DPO meetings, especially when they interacted with other WWD. NVCC may not be considered a DPO because it is not run by
someone with a disability, but multiple WWD in leadership positions mentored and worked with other WWD. One woman, in her forties, expressed before she came to NVCC and interacted with other PWD she felt too shy to expose herself to society. Many women like her detailed benefiting from interactions with other PWD. When asked if being in a DPO helped her, Jayanthi referenced CCO’s programs:

I get strength from committees and meetings. I get knowledge and I feel like I’m not disabled. I feel like this is nothing (gesturing to her arm) when I participate in those meetings. I get advice from them and I follow that and gain knowledge. I learned from the trainings that asked us to work bravely and courageously. I took a lot of trainings about leadership. I already knew how to sew, so I wanted to take the leadership program. There should be more programs like that, there are a lot of things to learn about.*

Altering the types and formats of trainings offered by CBR programs was a common topic of discussion and are detailed more in Chapter 3. Sharona, met through NRC, lived in a very rural location and echoed another common request regarding livelihood opportunities. When I asked her what her community believed about disability, she replied that in her area there are only a few PWD and that their lack of visibility made it hard to access opportunities:

Most people here believe we can’t do anything, but in (town) where most of the people are disabled, they don’t think like that and they know about our talents. Here, we are considered a novelty, we are only one or two people, so this community can’t understand our problems. Other areas have community programs that promote the confidence of PWD and explore their talents, but here we don’t have any opportunities like that.*

The desire for increased community exposure related to the talents PWD possess was a sentiment shared by many women. Like Sharona in the north, Hiruni, raised in the central region, also harbored feelings of isolation related to not knowing other PWD. Worried she was the only disabled person in her hometown, Hiruni spoke of being relieved after visiting CCO:

Moving away from home I was really scared. Then I came here and saw all the disabled people and I felt good because I am not that disabled. Seeing them do so much even with their disabilities motivated me, “okay they are doing all this work, I can do more, I can be like them.” Now I’m very happy. I feel like disability is an emotion, it’s all in our mind, like we imagine it. It’s all an illusion. I am not really disabled. I feel that way after being
here. Now I think like a normal person with no disabilities. I do my work, without worrying, and without thinking I’m disabled. It’s because of CCO, after coming here, because of Nayana’s leadership and guidance. She points out our faults and teaches us to do things in a right way. If she never pointed out my errors I would never learn. Before I came here, if I did something wrong, my family would always pity me, they wouldn’t punish me or ask me to redo anything, they would just say, “it’s okay, leave it there.”*

**Potential to Bridge Ethnic and Geographic Divides**

Reshika grew up in the east and was injured during the war. She talked about the importance of etiology and the societal difference she sees as a woman with a war acquired injury compared to a woman born with a disability. Although a recent Washington Post article noted some ex-combatants try to hide their disabilities in an effort to avoid state surveillance, none of the women interviewed for this research mentioned that practice (Robertson, 2018). This could be related to the sample of women who felt comfortable speaking with us. It is likely WWDs who wished to remain hidden would not agree to an interview, although questions about the war were not directly asked. Reshika clearly spoke of her struggles to balance serving her family and community in the face of people “trying to put her down.” She described how her community views PWD as two separate groups. The first is set are those disabled from birth, and the second, like her, were disabled in the course of their lives:

> I think we don’t have that many problems or face discrimination or any alienation because they know we are former members of “the group.” They don’t chase, or discriminate, or exclude us from any auspicious occasions. […] They discriminate against some people like us who have disabilities from birth.*

Gayathri similarly acknowledged her position of privilege compared to other WWD. She participated in over 10 trainings for PWD. We asked her, “based on your experience what kind of programs should be available for PWD?” She said her over participation meant there were still too many women who just sit at home, “we always go for trainings, but many women with disabilities they’re still at home. We go for all the things, but the other women should also go for
training.”* One woman, a widow with grown children, contacted through the NRC, lost her leg to diabetes later in life. She similarly contrasted her situation with other WWD who were unable to marry or those raising young children. She noted they have more responsibilities and encounter unique problems. Priya, married and raising adolescent daughters in the east, described her social position relatively as well, “I have a job, I work. I’m better off than other PWD. My sister who is unmarried used to stay at home before joining ECBO as a volunteer. ECBO tries to take them out for meetings and seminars.”* Thilini, introduced earlier, was contacted through the SRC. She lived independently with her mother through the support of kin networks in the community. Her goals for WWD specifically related to personal assistance:

Without dividing people and saying “they have a disability” or “they don’t have a disability” everyone should be treated equally, cared for equally, and they should be able to live happily and peacefully with everyone. Without neglecting PWD, they should care for them, the way they do for people who do not have a disability. There are people who can’t see, who can’t talk, and who are disabled in many ways, those who find it more difficult. So, they should be helped and should be cared for in an equal manner, even from the government. […] As a country, Sri Lanka could help the women, the government should help. I have seen and heard about people who have more difficulties than myself, who can’t even get out, who are bed-ridden and who can’t even eat or drink. The government should look into these matters and help more.*

This excerpt, and the one before, highlight tensions around discourse on disability. On one side, Reshika noted from a place of privilege that some WWD have a more difficult time related to their experiences with disability. On the other, Thilini questions the futility of grouping people on the basis of difference. Both viewpoints argue that society should have more concern for other PWD and like the excerpts above, this advocacy often took the form of providing resources to locate those who have not been “trained,” those less fortunate, or those still inside their homes. As noted in the quotes above, there are a multitude of reasons they remain confined such as stigma, inaccessibility, and poverty. Throughout the interviews, women acknowledged their own goals and successes while rallying for those who have not yet been included in society.
Home isolation was a common theme and experiences of war added additional complexities. Thivya’s story of being severely impacted by government surveillance was detailed earlier in this chapter. The intersection of war with safety, gender, and empowerment is a complicated one. Many Tamil ex-combatants interviewed attended empowerment trainings for WWD held by ECBO. They spoke of holding leadership positions in DPOs and other community-based organizations. Scholarship note nuances related to the war serve to challenge preexisting cultural customs and gender norms. Rajasingham-Senanayake (2004) questions long-term socio-cultural impacts that might arise from women’s participation in active combat in Sri Lanka, and asked if women will “be pushed back into the kitchen with a return to peace?” (p. 144). Reshika addressed this by saying society is trying to push her down when she really just wants to be a good wife and mother.

Findings show the analogy to being “pushed back into the kitchen” may be socio-culturally aligned with “being hidden inside” although as discussed throughout, this becomes more complicated at the intersection of disability and gender. While the kitchen analogy is relevant and related to gender norms, based on the findings, the terminology may arguably be outdated. Yet, many WWDs first and foremost wanted to help feed their families, often monetarily and literally, but they also wished to serve in their communities and advance the overall status of PWD in society. Rajasingham-Senanayake (2004) noted a failure to recognize and appreciate the gender-based social transformations brought on by women’s participation in war will stall the personal recovery and progress of women who have experienced trauma and who are working to navigate uncharted socio-cultural roles (p. 147).

Ramya benefited from a community-based mental health program many years prior. She met the facilitator of the program by accident at a government office and attributed their
immediate connection to her “ability to talk.” He asked if she wanted to participate in an upcoming counseling training and she agreed. Ramya said she cried a lot during the event. She felt very lucky to have been assigned to a group facilitated by him, a person she looked up to. He listened to all of her pains and talked with her directly. Her son was just an infant, she was injured, and she had lost her husband and home due to war. She suffered a lot during that time and was very stressed, almost to the point of suicide:

But after the training, the counseling sessions too, I felt lots of relief my mental stress. I took something from that training, and I came out from the all my suffering. […] From my perspective, whatever the CBR programs give, no one thinks about offering counseling. We need it because WWDs and PWDs are suffering. They hurt a lot. They are mentally stressed, and no one focuses on giving them relief from their mental stress. That’s a big issue. We need it. For me, had so many pains and problems. At that time, I was given many things at the time, many people and organizations gave me a toilet house, and other facilities. Yet I was not satisfied, and still I struggled. At that time, I was struggling and suffering pain until I participated in the counseling training. I had suicidal thoughts. It was very painful life for me. I didn’t have anyone to sit and listen my pains. Here there is no one.*

Ramya’s experience with counseling was transformative. She was the only interviewee who mentioned receiving such services. For her, some of the trauma and grief were alleviated through the program. Ramya said counseling should be included in CBR services, “whatever they are giving, whatever PWD and WWD receive, there is no one there to sit and talk with us and listen to us and what we want.”* Ramya said she is often chosen to participate in government and NGO programs because of her ability to speak. She said she stopped participating in programs because, “I developed a good ability to be alone and work on my own, and others need the opportunity more. Give the opportunity to them, to those who are struggling and stuck in the same place.”* She wanted community programs to include a focus on counseling and mental health, but noted counseling should not only target those with disabilities, “family members also need counseling. If we mobilize them, only then they will treat children
with disabilities kindly and with love. They will stop discriminating and saying, ‘no you can’t do this.’ Only then it will be effective.”* Many women, like Ramya, discussed feelings of discord related to the charity-based model of disability development. Desires to work, and obstacles they encounter in providing for themselves and their families, are detailed more in Chapter 3. The next section addresses feelings WWDs raised related to receiving handouts.

**Combating the Charity-based Model**

The charity-based model in a Sri Lankan context is a complicated one. Hundreds of years of colonization, decades of civil war, and recovery from natural disasters all shape the political infrastructure and development landscape. Historic and current practices combine to impact the opportunities available to WWDs in their villages. Sri Lanka’s cultural and religious context involves giving alms to community members for merit (Liyanage, 2017). During fieldwork I observed gift giving mostly occurred on auspicious anniversaries such as the donation of food to the CBR program on the death day of a loved one. One field officer I shadowed from SRC mentioned instead of donations of lunch from the community the women she worked would much rather have community alms in the form of bags of cement in order to improve buildings and construct toilets.

The need to provide services and items necessary to marginalized groups for overall well-being, and questioning who is responsible to provide these entitlements, is an important discussion. On one hand, charity as an intervention model is seen to maintain people in their marginalized positions through provision of resources, but not too many resources to imbalance a system that privileges the few who are “funding” the assistance. On the other hand, a neoliberal empowerment model argues more effective interventions would increase programs directed at self-improvement and individual functioning so people can earn access to basic needs.
themselves, such as the adage of “teaching a man to fish.” I do not doubt both models are well intentioned, but neither address systemic imbalances of power (ableism, sexism, discrimination) invisibly and forcefully marginalizing individuals to the point their basic needs are not met. Referring back to the adage, how can you fish if you are not allowed to join others at the pond? CBR programs in some form or another throughout this dissertation have reinforced certain aspects of both models. To acknowledge these programs and WWD operate and fight within an inequitable system is not to discount their fight, but contextualizes it and proposes alternative avenues for social change and intervention.

As discussed in Chapter 4, CBR sites in this research did not programmatically focus on providing health access or medical-related services for the women interviewed. All of the sites adopted neoliberal, rights-based views related to providing resources and services to PWD in order to promote individual involvement in income generating activities. These aims are not surprising given the WHO mandate to alleviate poverty, and the very real need for WWD to provide monetarily for their families. In addition to examining what is happening on the ground with CBR programs in Sri Lanka, this research aimed to problematize exclusively individual-focused efforts that often occur at the expense of addressing systemic barriers. In doing so, this research provides a wide critique of and a framework for community-based services.

Ramesh’s organization (ECBO) used to distribute materials, but they created a “dependence mindset again and again.” Instead, they now only provide trainings and personal development opportunities to PWD. The organization acts as a “facilitator, moderator, or a broker.” Pushpa, a leader in her DPO, and also associated with ECBO, shared a similar view. She said over 500 people come to their meetings, and she wants them all to be active participants, but some come with the expectation of getting something. She tells them, “We don’t
have anything but we will instruct you on what types of benefits or services you can take from
the government.”* Many women noted a desire to do their own work and combat notions that
they expect handouts or charity. Shamini’s experiences with disability-based employment
discrimination were noted in a previous chapter. She said when people provide donations it
makes her feel depressed and incapable of doing anything, pushing her further into despair:

What I want is to live happy with my family. To spend money on my family. Put my
effort in, and do something for them, because they have helped me with my education
and I have learned something. I have to make use of that and contribute to the family.

The women interviewed, with the exception of CBR leadership, did not have an active
role in determining the types of services that their CBR program offered. I do not know if the
field sites conducted any type of surveys or participatory evaluations to design or assess the
programs they offered. None of the women I spoke with mentioned being asked for their opinion
or feedback. They were more concerned about individual and community-based perceptions
surrounding the receipt of services instead of the content of the programs offered. Combating the
notion of passively receiving benefits from CBR programs was a prominent source of discussion
when talking about WWDs and their participation:

Some people think you come here to get handouts. They don’t get that we will be self-
reliant once we get job trained. […] We are not like that; we would like to work even
when we are home. […] You have to encourage them, show them which way is better,
while emphasizing this is good for their future. Even when they are here, some people do
not learn, they give up saying what they are learning is not tantalizing. […] We do
everything here it is not like we can expect others to help. Everyone is disabled here, so
we don’t expect from others. This might put some off. We can’t expect every comfort.
We work here just like we would at home. Nothing is permanent you know. (Neesha)

A middle ground between neoliberal and charity-based frameworks within this research
might be found at the intersection of human and civil rights. Specifically, Pogge’s (2005)
discussion of institutional reform relating to our negative duty “not to harm others by
cooperating in imposing on them an institutional order that foreseeable produces avoidable
human rights deficits” (p. 62). The freedoms often accorded to citizens, and recognition of their right to participation across various levels of society, should not be impeded. A major recurring theme in this dissertation is the systematic exclusion of WWD from spheres of society that are constitutionally afforded (e.g., universal health care and universal education) but that they cannot access because built and social environments constantly block their efforts for advancement.

Nondiscrimination laws and the remediation of physical barriers may be considered more fiscally attainable and separate from, for example, the provision of education; although the state’s responsibility to provide universal and targeted services marks an important area to be addressed in future discussion. Here, we are talking basics, the basic right to access that peers have but that WWD are blocked from. Some of the oldest legislation relating to access and services for people with disabilities centered on education for deaf, blind, and epileptic children (Education Ordinance, 1973); although it seemed Roshani, the only blind interviewee, did not benefit from the legislation. Addressing social issues does not entail a focus on individual development and responsibility; in fact, individualized discourses may instead detract from a needed shift toward addressing overall social development and societal responsibility. The WWD in this research did not want handouts; they wanted equal access and the chance to try.


I tell them always, there are a lot of people who have spoken to us and I say to stand up for your rights and fight back. We might have some short-comings but that doesn’t mean that our lives are incompetent. There are people who wear glasses after they turn 40. If they remove their glasses, they can’t see right? (Nayana, leader of CCO)

The WHO CBR framework defines advocacy and communication exclusively as “self-advocacy, which means people with disabilities speaking out for themselves… giving them the power to make choices, express opinions and make decisions which in turn builds their confidence and self-esteem” (WHO, 2010b, pp. 5-6). All of the women interviewed in this
research were expressive, speaking up about their interests, differences, and strengths. No one would argue against gaining confidence and communication skills, yet unfortunately in the CBR context, efforts to increase advocacy and communication appear to stop at the individual.

Many women felt they were born with an ability to speak, and some acquired personal communication skills after their involvement in DPOs and CBR programs. Several said they were appointed to multiple leadership positions within DPOs based on their “ability to speak.” Kumari, a leader within CCO, spoke for almost 2.5 hours the longest of any interview. At the end of her interview, she shared, “Now I can talk a lot. Because until 18 I didn’t talk. I listened until I was 18. Now I will be talking.” Ramya said she was chosen for a prominent public speaking role because of her “personality skill that gave her the ability to speak.” She lived in an army camp after losing her husband and house during the war. She shared a story of when a government representative visited the camp:

We met with her and she asked, “what type of problems do you have?” I am the one. I stood up and I spoke about my problems. I said we are severely affected by the war. I explained how I was suffering and my problems. I strongly and frankly explained my problems and our struggles on behalf of my village. I also told her, “you’re the only person we have, you know. You should be concerned about our needs and challenges. You should facilitate and help solve our problems. We have many needs that you should support.” I just explained. She noticed me and my words, and my speech touched her.*

Ramya attributed her ability to speak to later securing funds for a preschool in her community. Several women proudly shared their roles in co-founding and advising DPOs. Many served as leaders in their communities. We interviewed Gayesha, in her late forties. She was associated with SRC and also actively involved with many community-based initiatives, including advocacy related to children with disabilities in her community. Her father sat silently for the hour-long conversation. At the end of our interview, he began crying and shared:

In this house as parents we educated her, guided her to the right path. Today only, I got to know how much of a social service she has done for society and what she is doing. I am
really happy. Even with this disability the fight she is doing, the social service she is doing!

Yalini, living in the eastern region, also assumed multiple roles in community-based leadership positions. She was one of many women interviewed who co-founded a DPO. Yalini was appointed president, secretary, treasurer, and served as an advisor to various community organizations (e.g., DPO, Rural Development Society). All of her positions were volunteer-based and unpaid so she sometimes had to prioritize work over service to her community.

When asked about the biggest issue she currently encounters, Reshika said every time she has an opportunity to get ahead, she feels like the community is pulling her back. Living in the east, she found the strength to overcome the pressure to “stay down” through the support of her husband, parents, and sister. Reshika elaborated about her status as a woman and ex-combatant who leaves her village for social, work, and athletic events:

If a boy or if a man with disability does what I do, the people wouldn’t talk a lot, but as a woman I experience it. People try to send me back by saying negative words, they gossip and ask, “why do you leave your village,” and they focus on how we speak up. They think, “how can we talk to send them back or hurt them?” They gossip a lot to negatively spoil our names. They say because we fought that we want to show our guts and have big egos. They talk, but I don’t care much about that because I have a family and I should be genuine for them. […] That’s the community’s nature so I don’t want to worry about that. I just want to balance social service and be a good, responsible wife.*

Socially constituted barriers are prevalent throughout this dissertation. Data presented earlier in the chapter reveal specific ways gender overlaps with disability, marriage status, and gossip. Reshika clearly states this in the excerpt above. She and the women she traveled with intimately know of the social consequences of doing so and still persist in utilizing opportunities to leave their village. Reshika addressed the ways gender influenced her status in the community, both through her role in the war, and as a wife and mother.
WWD are often kept inside their homes, as noted throughout this dissertation. When they do go out in public, society sends messages they are seen as incapable of agency and in need of assistance. Kumari, a teacher at CCO, shared a story of when she led a group of students on a fieldtrip. The program required a lot of walking and collecting information to learn about the significance of a historic monument. Although she was in charge, people would interrupt her class to ask why she was “walking around like that?” Multiple times, she had to explain to strangers that she was walking with her students. She felt insulted by their questions, and at one point reprimanded someone who asked her:

When I go on the road and since I’m disabled, people think I’m always going to get medicine, even if I’m going to the bank or somewhere. People will ask me questions, “Why am I going alone?” or “Why is nobody available to go with me?” They try to hold me and help me to walk. They think I’m going to get medicine and that I would need the help of others and cannot be independent. I feel like hitting them. I have scolded some people especially when it kept occurring.

Multiple women, like Kumari, shared experiences of being hyper-visible in society when leaving their homes and traveling outside of their villages. Many detailed experiences of people staring or pointing at them. Kumari took these negative social interactions a step further and called out people for being rude, assuming she was incapable based on her appearance. As she noted earlier, after many years of listening, she finally found her voice and planned to use it.

An Emerging Politics of Disability

We contacted Amanthi through CCO. She knew other disabled women who were locked inside their house when their family leaves, “they shut the door and lock them inside and go.” In contrast, when her mother left to run an errand, Amanthi stayed at her house in the village “without any fear of opening doors.” Amanthi’s mom attends DPO meetings, and interacts with other parents who say they have locked their daughter inside the house to attend. Amanthi said her mom always replies, “I don’t do that, and my daughter is okay at home, it is not nice to lock
someone in and then go.” The uniqueness of this excerpt is Amanthi’s mother not only treated her daughter the same as her peers in practice, but Amanthi was proud of her mother for going against expectations and scolding parents to treat their children better.

Hiruni, introduced earlier, was given permission by her father to live and work at a CBR program hours away from her hometown. We discussed her transformation within the CBR program earlier in the chapter. When asked what is needed to change the mentality of parents who keep their children with disabilities sheltered, Hiruni replied:

We need to make awareness programs among families. Show them the world, what a disabled woman can do. Sri Lanka is always behind. People with disabilities in other countries are very advanced and they are achieving their goals. You should show those videos to parents and all the family members of people with disabilities and raise awareness that we can also do this. At least we can try. Show these videos and make the family aware and motivate them to let us try things. They would help us, they would motivate us, they would push us do to more of these programs. Now my family knows about me and my capabilities and potential.*

Hiruni’s quote not only addressed tendencies for families to shelter their children with disabilities, but also called on society to learn about the talents of PWD—to be more aware of the things they can accomplish. In her own family Hiruni said she was not trusted to do anything. Her parents and siblings did everything for her. After working at CCO for many years, she shared proudly how her family now considers her as capable and responsible. She told a story of when her father was admitted to the hospital and how, out of all her siblings, she cared for him and helped with managing his care. Her father’s brief illness shaped the way Hiruni’s family viewed her, and solidified her proud role as an active contributor within her kin network. The desire for opportunities to use skills, and to be encouraged at a young age to develop new ones, are detailed throughout the dissertation.

Hiruni’s advocacy for PWD through the education of families and societies signals a growing paradigm shift that considers disability as a social status and social group. The contrast
between the isolated and the social is made clearer by the formation of DPOs. Pushpa, introduced earlier, founded a DPO in the east with a group of women. Their motivation to form a group was because they had an “idea to take out the people with disabilities from home.”* They spoke with parents because they do not know, “to let their kids out, and they don’t know much about people with disabilities. They do not know anything about our rights, but in our DPO, we instruct them. They should understand what type of rights we have.”* Women’s groups in Sri Lanka have a long history of social activism (Jayawardena, 1986), and the interviews show the strength and resolve of the individual women in this research. Their struggles to form collective power through social alliances have the potential to fuel the emergence of a politics of disability (Garland-Thomson, 2011). However, the act of transformation is not theirs to bear. It requires a dismantling of oppressive systems, harmful beliefs, patriarchy, ableism, and discrimination. Therefore, this burden of change belongs with all of us.

Summary

This chapter included themes related to women’s movement and mobility. Movement is constructed with a wide perspective related to physical and social spaces; as well as in relation to the inverse, isolation and stasis. Themes detail cascading impacts of invisibility and gender roles in relation to women’s resources and movement. As the findings detail, the invisibility of women; expectations they stay within their villages and homes; pervasive sexual harassment; and the lingering impact of long-lasting nation-wide violence, all combined at various levels to maintain and justify restrictions on their movement. Evidence indicates the CBR system, as it is designed and implemented, operates within an unchallenged neoliberal discourse of development. This development is especially salient in relation to ways structural barriers are ignored and instances of how WWD are expected to overcome them.
The women included in this dissertation occupied various forms of resistance. They created alternative paths as agentic daughters, mothers, sisters, and wives; they disrupted the status quo of community-based marginalization maintained by patriarchy and ableism. They are the spirit of Sri Lanka, resilient, strong, passionate, and optimistic about the future. Their struggles and activism clear a pathway for communities to recognize the bright future women and girls with disabilities have in Sri Lanka. The upcoming conclusion briefly ties the findings of Chapters 3 through 5 together, recommending a potential path forward in order to address structural inequities in research and practice. It carries the spirit of social movements around womanhood and inclusion, propelling the snapshot of experiences detailed at length in this dissertation in a call for community-based change and community-based action.
CHAPTER 6. DISCUSSION AND CONCLUSION

The overall purpose of this study was to contribute to existing literature on experiences of gender and disability within the context of development and rehabilitation practice. Previous research focused on interviewing service providers, or, more rarely, WWDs within CBR programs. My research expands on this to show how the overarching framework of CBR, specific cultural and geopolitical systems, and discrimination all impact women’s experiences of disability and CBR in Sri Lanka. I ethnographically investigated ways WWD navigate and challenge structural barriers. This interdisciplinary approach was sourced from feminist scholarship, disability studies, sociology, and anthropology. In particular, I investigated social issues not addressed, and possibly maintained, within the current CBR framework. This research was guided by themes related to the experiences and goals of WWD, and an ethnographic analysis of social and built barriers altering their potential for mobility.

An ethnographic framework was best suited to explore the above areas of inquiry and allowed for each interviewee to share their experiences through semi-structured interviews. The methods provided descriptive observational data within many of their homes, CBR programs, and communities. They enabled me to draw upon transnational research and theories to contextualize and inform the newly emergent findings. I conducted 13 months of fieldwork as well as interviews with 46 WWD and 6 CBR program leader. Themes arising from the data included systematic and social failures occasioning long-lasting influences related to educational and economic mobility, social mediators of health and pervasive discrimination, and contexts of disability invisibility and gender-roles in propelling a social movement. The findings are contextualized using consideration of decolonial, transnational disability, and third-world feminist movements. This research is grounded in understanding personal experiences in relation
to the universal. In privileging the specific and the local, we illuminate the universal (Mohanty, 2003). Here, universal processes of exclusion are evidenced by local socially mediated patterns of exclusion and marginalization based on difference and gender. These findings corroborate previously documented experiences of WWD in the global South, and further identify social barriers for WWD in Sri Lanka. This chapter concludes with a discussion of implications and recommendations for future research.

Past research has documented CBR’s failure to combat gender-related social issues based on the overuse of a medical intervention framework (Bualar & Ahmad, 2009). However, this research shows in Sri Lanka, similar to India (Chaudhry, 2019), the potential for community-based social transformation through CBR is intricately bound and stifled by an individual neoliberal framework of intervention within a post-colonial context. Research has examined limitations of the CBR framework and failures in addressing systemic social barriers for PWD, but none adapted a specifically gendered lens along with participant observation within multiple CBR sites. These findings identify ways pervasive ableism operates within specific cultural contexts and locates specific areas in need of social intervention.

Chapter 3 contextualized past experiences within an education system rampant with ableism that failed WWD. These early experiences significantly impacted later employment opportunities, where ableism and sexism were intertwined. The women interviewed were aged between 20 to 70 years old and yet each of their past experiences with harmful social attitudes and physical inaccessibility could have taken place in the present. They were keenly aware of this and resolutely advocated for social change on behalf of children with disabilities. The barriers of their past persisted in many forms; however, they fought hard to secure a better future for their own children. The effects of women’s past experiences with education were
unchangeable in the present, where highly gendered employment sectors enforce unequal access to jobs. There were no avenues of recourse to continue their education as adults and they desperately wanted a chance to display their skills. Layers of disablement and disadvantage throughout education made securing financial stability difficult, and a narrow focus on individual training fails to challenge or change this.

Chapter 4 brought us more into the present, although temporal distinctions within such brief periods of data collection are ambiguous. I relied heavily on these snapshots, scenes within which the interviews and observations took place, to present data on broad social aspects mediating overall health and well-being. I noted ways interviewees presented themselves, their stature, tone, and facial expressions during each interview. This data necessarily expanded concepts of health in order to incorporate a broad analysis of the positions WWD occupy in society. Their words confirmed what I could plainly see—adequate housing and transportation were major social and financial barriers. Also, of course, housing was a theme woven throughout the data. In this context, the home represents ideals of health, safety, and status; as well as isolation, hardship, and imprisonment. This juxtaposition may also be useful when conceptualizing relationships to physical bodies. To advocate for better rehabilitation technologies (e.g., prostheses and assistive devices) is not to discount disability as a social category and does not detract from demands for social change. Both are important and depend heavily on a context where sexism positions men as resource bearers and women as dependents.

This work also locates ways rurality, class, physical difference, and pervasive ableism further impact women’s well-being.

Examples of rampant social isolation, discrimination, and neglect are present on almost every page of this dissertation. Chapter 5 highlighted ways women work to mitigate sociocultural
sexist and ablest barriers that call for their physical isolation and invisibility. Avenues of camaraderie related to social inclusion, such as participation in community groups or DPOs, were briefly explored. This awareness and other potential pathways to building the collective social influence needed to address systematic discrimination should be investigated in future research. Where the previous chapters touch on past and current social aspects of disablement, Chapter 5 aimed to propel the aim of intervention into the future. Identifying social complexities related to the intersection of gender, disability, class, and geography to provide a context for change and markers of ways society is changing. The evidence shows ways these oppressive realities are negotiated and challenged by WWD and their families.

All the chapters in this work come together to inform a desperately needed consideration of social barriers related to gender and disability. Qualitative representations of experiences within interventions serve to critique and question the current framework of intervention and larger structural influences that prevent societal progress and improvement. The current chapter uses the data to outline areas where we must redirect the role of development toward the rehabilitation of society and calls for interdisciplinary research to incorporate critical and intersectional models of disablement.

**Exposing the Limitations of the CBR Framework**

PWD, particularly WWD in low-resource countries, have been systematically marginalized within their communities. Their experiences are almost entirely absent from the literature. The CBR matrix promotes social inclusion and opportunities for PWD, yet the overarching framework does not incorporate a targeted intervention of social change, nor does it adopt an intersectional lens to consider ways gender and other social locations impact the efficacy of the framework. In choosing to focus on experiences of WWD for this study, the
findings of my dissertation are positioned to inform multiple gaps that persist in contemporary community-based disability research and practice. This work is in line with previous researchers who call on intervention scholarship to consider ways cultural and gender dynamics intersect and impact the socialization opportunities for individuals with disabilities (Bualar & Ahmad, 2009; Gulati et al., 2011; Mendis, 2004; Zaviršek & Herath, 2010).

**Recommendations and Implications: Society’s Disabling Role**

All CBR program leaders discussed ways society marginalized women they served based on both gender and disability. Surprisingly, male leaders more clearly discussed aspects of social barriers that women face in relation to their gender. Many brought up the importance of marriage and family, including the restrictions WWD encounter in family life. A similar pattern emerged in relation to war. Arunadhan (NVCC) and Ramesh (ECBO) discussed aspects of gender-based stigma, specifically for women who were impacted by the civil war. The social awareness many leaders expressed in the interviews posits an important finding, one that may be viewed as an emerging starting point from which to create conversations around improving the framework of CBR. This would entail designing programs using the experiences of WWDs and thus a focus on prioritization of community-level change over discrete individual trainings.

It is clear many programs worked to improve the individual status of WWD through livelihood trainings and skill development. It is less clear how they made an impact at the community level (e.g., increasing environmental accessibility or combatting stigma and discrimination). Many WWDs interviewed also clearly identified society’s role in keeping them on the margins based on their gender, disability, or class. A majority acknowledged they could not fully benefit from the CBR trainings because society was unaware of their talents. This identifies clear problems with the existing CBR framework, and evidences failures with the
intervention system in practice. There is a theoretical and practical need to critically examine “disability-inclusive development,” and to better understand ways embodied experiences of disability in the global South can and should inform, shape, or transform current practices (Grech, 2016). What we need is a model of community development related to disability.

Jnanabrata Bhattacharyya’s (2004) model of community development entails two major goals: individual attainment of solidarity and agency. He attributed the erosion of these goals to industrial capitalism and the rise of the nation-state, yet also placed the burden of change on individuals themselves or on the collective efforts of self-help groups. This theory of community development lacks a description of methods and techniques to enact efforts toward community-based change. His suggestion of increased political clout and networking are undeniably useful tactics, yet they do not address the main issue: How do scholars and practitioners increase solidarity or universal “respect,” in the present case, for people with disabilities? Bhattacharyya (2004) noted solidarity “ grows out of face-to-face relations” (p. 26), but what macro-level methods and techniques are available when societies as a whole are not accessible physically or socially; where oftentimes meaningful personal encounters do not exist at the community level. Altruistically attributable to a lack of theoretical and methodological guidance, the default starting point in CBR practice and research has been to place the burden of change on caregivers, often women in poverty, and on PWD themselves (Chaudhry, 2019; Erevelles, 2011).

Is “Development” a Bad Word?

I do not wish to use this research to critique the people working so hard within the CBR organizations that influence the lives of WWDs. Instead, I aim to systematically and critically question frameworks, and overarching cultural and social beliefs, that impact the structure and design of the programs being implemented. In this context, my opinion is development is not a
bad word; it is an inevitable process. Instead of being outcast wholesale, development should be continuously reformed, questioned, and improved based on the experiences of the groups it aims to serve. This evolution is in contrast to common top-down research and evaluative approaches. The term development rightly bears the burden of constantly needing to prove its relevance and social validity based on the perspectives of those it purports to serve.

Development-related programs and research are inherently designed by individuals and organizations with social, political, and economic power. The designers are not located on the peripheries of society like those impacted by their programs. The fact these programs operate within our capitalistic reality does not mean critical studies scholars should fight for their abolishment. On the contrary, this research shows that sexism and ableism in the findings related to CBR programming evidence larger-scale power relations within society that could very well be addressed through development programs designed and informed by those on the margins. A shift is needed in order to change the behavior and beliefs of those hindering true community development, those maintaining inequitable power relations. In designing this research to show how particular struggles and locations are universally significant, I aim to bridge understandings of “collective differences” and solidarities across boundaries (Mohanty, 2003, p. 191).

The CBR programs recruited for this research serve as a mediator between society and WWD. They identified WWDs and worked within their families and communities to provide services. They serve a valuable role in increasing and solidifying the connection between WWD and greater society. The issue, as shown in the findings, uncovered the developmental impact of CBR as only unidirectional—upon the women. It is not difficult to imagine CBR programs harnessing their existing community efforts to create a community-based model of development that flows bi-directionally in order to provide resources to WWD as well as to inform and
implement large-scale change within society. This action would facilitate meaningful community-based change programs determined by WWDs instead of for WWDs. The methods used in this research provide a critical turning point where bi-directional informational channels of development could begin.

**The Burden of Change Must be Redirected to the Societal Level**

If the organization of the social actually generates the barriers and problems associated with disability, then the negative economic, social, and personal consequences following from disability are neither natural nor inevitable. (Jung, 2011, p. 266)

Community-based programs operate within complex networks of government and civil society organizations. Professionals, activists, and community leaders from a variety of fields (e.g., law, health, education, civil service, and non-governmental organizations) work together to influence policies, programs, and the services available to WWD. It is clear the CBR programs studied in this research do not have the data, support, or programmatic resources to more completely address the social issues presented in this dissertation. However, I argue they can begin to address them through program evaluations that are inclusive of the experiences of WWD and that identify specific goals of the populations they serve. For example, women from some programs were more impacted by a lack of transportation to access health care, while women from another program wished to combat systematic gender and disability-based discrimination from the government that prevented them from getting their driver’s license. It is clear that pervasive social issues hinder the impact of CBR services, yet the majority of programs do not target community-based education, activism, or intervention as priorities. The CBR framework has built-in participatory elements such as calling for programs to create DPOs, but these groups are not inherently evaluative and instead operate within an empowerment
framework that once again problematizes the “mindset” of PWD (WHO et al., 2010b, p. 1). This is in contrast to challenging the mindset of ablest and discriminatory communities.

It is clear the CBR matrix was not useful in serving the majority of women in this research, as their perspectives, social positions, goals, and strengths were not incorporated in the interventions offered. Societal expectations and programs focused exclusively on identifying individual solutions to widespread structural barriers are futile and inefficient. The current system omits acknowledging and acting upon systematic barriers; therefore, they remain unaddressed. The directional shift I propose for CBR services likely requires a fundamental reframing and restructuring of the intervention sectors. Based on the contributions of this research, the sectors must incorporate an intersectional lens that includes the experiences of women and problematizes processes of social disablement, instead of locating the problem within PWD themselves. Funding mechanisms also heavily impact the services CBR programs can offer to the people they serve. Future research should examine ways top-down funding sources determine the focus of particular CBR interventions. The critical systems lens of disability applied in this research sets the stage for us to intervene on the social nature of disability (Bickenbach, 2012).

**Failure of State Responsibilities.** Many of the themes connect to the government’s responsibility to invest in education, health, and transportation services that serve all of its citizens. There is a glaring gap in the public sector related to constitutional rights of Sri Lankans with disabilities. Government programs linked to housing, medical care, and monthly financial assistance were present in the lives of WWD; however, navigating local and national politics was a barrier for many. A lack of transparency related to Samurdhi benefits and other support programs led to many women disengaging from programs for which they were likely eligible.
Although none of the women I spoke with requested help navigating channels of assistance, this is an area of future research and practice that will have a significant impact (Samararatne & Soldatic, 2015). Harvey (2005) notes recognizing the failure of neoliberalism as a “failed utopian rhetoric masking a successful project for the restoration of ruling-class power” will set the stage for mass movements that demand economic security and justice (p. 203).

One of the most prevalently discussed topics related to gender equality in Sri Lanka is that of women’s political representation. Sri Lanka boasts the status of electing the first woman to head a nation in the modern world (Kearney, 1981). Yet the election of a woman in 1960, the widow of an assassinated prime minister, did not meaningfully promote the status of women in politics or women in general (Jayawardena, 1986; Kearney, 1981; Rajasingham-Senanayake, 2004). A 2017 UN report notes women’s representation in politics and public office may be an avenue to address economic inequalities they encounter in Sri Lanka. The report welcomes a 25% quota for women in local government and a 30% quota for political party nominations of women at the provincial level, yet also acknowledges women bear a disproportionate amount of household labour and may be hesitant to compete in precarious political environments.

Darini Rajasingham-Senanayake (2004), describes a less optimistic view of women’s leadership roles in politics, arguing women’s political involvement can often be labeled “dynastic tendencies” that developed out of “gendered realities of political power and violence” (p. 143). Positions often occasioned by the death of a close male relative in power, these roles are paired with patriarchy and ethnocentrism. Rajasingham-Senanayake correlates this structural political violence with political parties who co-opt secular groups in a “hostile ethno-nationalist” climate that furthers ethnoreligious divides (p. 162). In research related to war acquired disabilities, Kandasamy, Soldatic, and Samararatne (2017b) located potential avenues for
gender-based disability activism across regions and ethnicities. These and related programs should be further studied in relation to community development and mobilization.

In addition to questioning the human development priorities of the previous government, there remain significant concerns related to war crimes committed by the Rajapaksa government (Ives & Bastians, 2019). Areas of government transition are important to note, especially because in late 2019, the brother of the previous president who served as the defense chief from 2005-2015 was elected president. Soon after, he appointed his brother, the previous president, as the head of parliament. If we assume the current government will return to a focus on infrastructure development, it should be noted while some scholars call for an increase in transportation accessibility (Ahlström et al., 2011), others argue building roads in Sri Lanka is not essential, but is instead a Sinhala-Buddhist nationalist “process of state territorialisation” to consolidate control in minority areas (Ruwanpura et al., 2020). The current government appears to be a reconfiguration of the pre-2015 regime, and marks a significant turning point away from the once anticipated path toward social development and peace and reconciliation in Sri Lanka.

Tamil community leaders in this research note the significant impact of war in disenfranchising women’s opportunities for societal acceptance and integration. The absence of discussions around ethnicity every single one of the women’s interviews is worth noting. This is an area in need of future inquiry, especially in light of efforts toward post-war peace and reconciliation.

**Intersectional Models of Disablement**

This dissertation addressed complexities between disability and rehabilitation. The findings demonstrate a fundamental contradiction related to the premise of rehabilitation within the current CBR framework. The majority of women, by all intents and purposes were rehabilitated, only to find their mobility and goals hindered by external barriers within a society
not ready to accept them. Past research suggests teachers and medical students need more exposure to PWD. Many women expressed ideas and desires that align with this recommendation. They believe exposing their talents and capabilities to society would be a large part of the solution. In drafting my research proposal, I understood the theoretical and ethical implications of studying medical-based interventions of disability, but did not expect a rights-based framework like CBR to accompany neoliberal expectations of rehabilitation and complicate the notion of empowerment. Subsequently, this research creates additional questions related to empowerment and rights-based discourses that are often accepted without critique in disability intervention research.

My ethnographic methods identified and framed multiple layers of stratification WWD experienced. This research and analysis aimed to adopt a paradigm shift away from forming monolithic representations of WWD. Instead, I hope to complicate and honor differences in gender and disability perspectives while situating the various experiences gathered within specific social and cultural environments (Hartblay, 2020). As noted, CBR programs do not often address social avenues of marginalization and may maintain them through non-participatory top-down intervention designs. The extent to which gendered exclusionary systems discussed in the findings have been shaped by hundreds of years of colonization, a long civil war, rapid globalization, and poverty must also be investigated further.

**Across the Lifespan.** It is well documented that PWD globally, regardless the GNI of their country, experience worse health outcomes, lower levels of educational achievement, less economic participation, and higher rates of poverty than their peers who are considered non-disabled. The current findings strengthen the argument against pathological explanations for these disparities. The struggles of PWDs are a result of socially-determined barriers hindering
their physical and social mobility and preventing their full inclusion in society. Poor individual outcomes for PWD are well documented in research discussing inequities, yet the systematic environmental barriers they encounter are far less documented. It is imperative rehabilitation-related research critique these inequities within the context of societal opportunities and constraints (Staudinger & Bluck, 2001).

We might also understand the data through a life-course approach that acknowledges disability “carries a different significance for people of different ages and stages of life,” therefore the current participant pool, with perspectives spanning generations, resists over-simplifying experiences of disability and identifies unique ways disabling societies operate, ultimately improving disability related theory and scholarship (Priestley, 2003, p. 4). Themes expressed in the narratives are organized and governed by society, flowing across key experiences noted within the women’s interviews. They begin in childhood and progress through cultural markers of adulthood, such as getting married and participating in economic and community life.

Very little literature exists related to the social exclusion of WWD in Sri Lanka and the global South. The longitudinal impact of these barriers and their developmental ramifications remain unaddressed. We know social isolation hinders development, and there is a need for future research and practice to consider ways specific etiologies of disability, age, gender, and levels and severity of exclusion intersect to impact the long-term well-being and development of socially isolated WWD. The profound impact of family beliefs and practices concerning the exposure of children with disabilities in society must also be studied more in-depth. Areas of inquiry might examine beliefs that work to instill positive identity development, and those that treat stigma held about disability by community members.
Themes presented in this dissertation show complex social and personal processes and the ways they work to facilitate, or more often prevent, the participation and inclusion of WWD. Narratives revealed multiple discriminatory attitudes and practices (Garland-Thomson, 2005), particularly when it came to marriage and access to the outside world, whether it be simply leaving the house or traveling on public transportation. The data articulates the clear power family-systems hold in potentially accessing or progressing through multiple life course events, first in structuring opportunities for physical mobility outside of the house as children and then in facilitating or hindering social development as adults. As noted, there are multiple interrelated factors maintaining the location of both gender and disability on the margins of full social participation, often (although not always) across geographic, class, and ethnic boundaries.

**Calls for Interdisciplinary Research.** There is very little data available related to demographic characteristics and qualitative experiences of PWD in Sri Lanka, and an even smaller amount available on WWD in Sri Lanka. To begin to remedy this, global South and South Asia researchers must incorporate disability into their research purview. Disability studies scholars must consider a transnational perspective in conjunction with decolonial frameworks that privilege local contexts and experiences in order to identify and critique new forms of imperialism, and development researchers must be expected to incorporate all of the above. This study furthers calls to systematically address power relations evident in policies, practices, and communities that continue to perpetuate disablement. Ethnographies are well suited to acknowledge the political accountability of research, in the form of useful contributions to the local community, and recognize the value of feminist-informed praxis (Enslin, 1994).

This work is situated within a global context of disability and international development. While the current focus of disability as a universal and complicated phenomenon is admittedly a
broad area of inquiry with which to actively engage, it is also one connected by shared struggles within societies dominated by ableism, sexism, neocolonialism, and neoliberalism. In addition to seeking out active political engagements, ethnographers should also work to disrupt, consolidate, and re-distribute resources (i.e., political, emotional, financial) to groups who are connected in order to more easily build collective change and empowerment (Enslin, 1994). Aspects of collective empowerment and ways it is fostered, especially in relation to DPO involvement should be examined further. Basing the research within established CBR programs, interviewing program leadership, and recruiting women beneficiaries of the programs, increases the potential for this research to support women’s calls for social justice and equality.

This dissertation aims to address gaps existing in literature related to the experiences of WWD. In doing so, I question ways disability and rehabilitation are politically, culturally, and socially constructed. The results bring into question the foundational framework of CBR and offer rare on-the-ground perspectives of these programs. Efforts spent on interventions that ignore knowledge and experiences of PWD ultimately waste resources and fail communities (Bular & Ahmad, 2009). Women’s experiences within the intervention sector have been effectively absent and lead to an underrepresentation concerning the realities of their positions relative to service provision. The themes in this research document a need for communities and research to be more inclusive, and thus obligate scholars to shift the burden of change to where it belongs—not on PWDs, but on families, communities, and organizations that often maintain economic, political, and social processes of discrimination and isolation. Findings throughout this dissertation show the existing framework is inadequate to address many important issues, specifically, the social barriers at the intersection of gender and disability.
Conclusion

This scholarship reveals previously unaddressed fault lines within the WHO CBR framework. Questions and issues arise from this work related to how CBR programs are conceptualized, delivered, and researched in relation to the perspectives and lived experiences of WWDs. Glaring gaps in the foundation and implementation of CBR programming ensure systematic barriers will remain ignored on a wholesale level. Socially maintained struggles at the intersection of gender and other marginalized locations such as sexual orientation and class remain unaddressed within the current framework. International development and rehabilitation projects should not be readily dismissed by critical theorists or disability advocacy groups. Organizations and people will always be willing to provide individualized rehabilitative interventions. This study provides insights into several ways the discourse on disability rehabilitation and intervention can be redirected to where efforts are most needed: addressing processes of social disablement.
Table 1

Field Site Interview Characteristics and Information

<table>
<thead>
<tr>
<th>Site</th>
<th>Observed Primary Focus</th>
<th>WWD Interviews</th>
<th>Interview Range (minutes)</th>
<th>Interview Average (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NRC</td>
<td>Physical Rehabilitation</td>
<td>4</td>
<td>23-54</td>
<td>38</td>
</tr>
<tr>
<td>NVCC</td>
<td>Vocational Training+</td>
<td>6</td>
<td>23-44</td>
<td>38</td>
</tr>
<tr>
<td>SRC</td>
<td>Physical Rehabilitation and Vocational Training</td>
<td>15</td>
<td>24-93</td>
<td>59</td>
</tr>
<tr>
<td>CCO</td>
<td>Small Interest Loans+</td>
<td>11</td>
<td>25-140</td>
<td>66</td>
</tr>
<tr>
<td>ECBO</td>
<td>Individual Training</td>
<td>10</td>
<td>64-123</td>
<td>92</td>
</tr>
</tbody>
</table>

Note. (*) First step interpretation only. (+) Part of program includes housing and food provision.

Table 2

Descriptions of Sri Lankan Education Levels

<table>
<thead>
<tr>
<th>Grade</th>
<th>Age</th>
<th>Title</th>
<th>Grade</th>
<th>Age</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5-6</td>
<td>Primary Level</td>
<td>8</td>
<td>12-13</td>
<td>Junior Secondary</td>
</tr>
<tr>
<td>2</td>
<td>6-7</td>
<td>Primary Level</td>
<td>9</td>
<td>13-14</td>
<td>Senior Secondary</td>
</tr>
<tr>
<td>3</td>
<td>7-8</td>
<td>Primary Level</td>
<td>10</td>
<td>14-15</td>
<td>Senior Secondary (O-L)</td>
</tr>
<tr>
<td>4</td>
<td>8-9</td>
<td>Primary Level</td>
<td>11</td>
<td>15-16</td>
<td>Senior Secondary (O-L)+</td>
</tr>
<tr>
<td>5</td>
<td>9-10</td>
<td>Primary Level</td>
<td>12</td>
<td>16-17</td>
<td>Senior Secondary (A-L)</td>
</tr>
<tr>
<td>6</td>
<td>10-11</td>
<td>Junior Secondary</td>
<td>13</td>
<td>17-18</td>
<td>Senior Secondary (A-L)+</td>
</tr>
<tr>
<td>7</td>
<td>11-12</td>
<td>Junior Secondary</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. +Certificate exam at end of the Grade.
Figure 1

*CBR Matrix (WHO et al., 2010f)*
## Appendix A

*Acronyms and Abbreviations*

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>A-L</td>
<td>Advanced Level (A-Level)</td>
</tr>
<tr>
<td>CBR</td>
<td>Community-based rehabilitation</td>
</tr>
<tr>
<td>CBSL</td>
<td>Central Bank of Sri Lanka</td>
</tr>
<tr>
<td>CCO</td>
<td>Central Community Organization (Pseudonym for field site 4)</td>
</tr>
<tr>
<td>DCS</td>
<td>Department of Census and Statistics</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled people’s organizations</td>
</tr>
<tr>
<td>ECBO</td>
<td>Eastern Community-based Organization (Pseudonym for field site 5)</td>
</tr>
<tr>
<td>FO</td>
<td>Field officer</td>
</tr>
<tr>
<td>GNI</td>
<td>Gross National Income</td>
</tr>
<tr>
<td>INGO/NGO</td>
<td>International- /Non-Government Organization</td>
</tr>
<tr>
<td>LMIC/UMIC</td>
<td>Lower- /Middle-Income Countries</td>
</tr>
<tr>
<td>MI/ID</td>
<td>Mental illness /Intellectual disability</td>
</tr>
<tr>
<td>NRC</td>
<td>Northern Rehabilitation Center (Pseudonym for field site 1)</td>
</tr>
<tr>
<td>NVCC</td>
<td>Northern Vocational Community Center (Pseudonym for field site 2)</td>
</tr>
<tr>
<td>O-L</td>
<td>Ordinary Level (O-Level)</td>
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<tr>
<td>PWD</td>
<td>People with disability</td>
</tr>
<tr>
<td>SRC</td>
<td>Southern Rehabilitation Center (Pseudonym for field site 3)</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>WBG</td>
<td>The World Bank Group</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WWD</td>
<td>Women with disability</td>
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</tbody>
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Appendix B

*Graphic of “National Data Estimates of Women with Disabilities in Sri Lanka” (DCS, 2014)*

*Proportion of Population (5 Years and over) with Difficulties According to District by Type of Difficulty and Sex (Female)*

Provisional Data Based on the 5% Sample (DCS, 2012)
Appendix C

*List of Women Quoted (page 1 of 3)*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age Range</th>
<th>Disability Etiology</th>
<th>Education</th>
<th>Marriage Status</th>
<th>Living Arrangement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geetha*</td>
<td>Early 60s</td>
<td>Acquired/Fall</td>
<td>Grade 7</td>
<td>Married</td>
<td>With husband</td>
</tr>
<tr>
<td>Tharany*</td>
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<td>Developmental/Polio</td>
<td>University</td>
<td>Married</td>
<td>With parents</td>
</tr>
<tr>
<td>Sharona</td>
<td>Late 20s</td>
<td>Acquired/War</td>
<td>Grade 10</td>
<td>Married</td>
<td>With husband</td>
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</table>

**Northern Rehabilitation Center (NRC) Tamil**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age Range</th>
<th>Disability Etiology</th>
<th>Education</th>
<th>Marriage Status</th>
<th>Living Arrangement</th>
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</thead>
<tbody>
<tr>
<td>Ajanthani*</td>
<td>Mid 30s</td>
<td>Unknown</td>
<td>Grade 11</td>
<td>Single</td>
<td>Dormitory</td>
</tr>
<tr>
<td>Chithra*</td>
<td>Mid 30s</td>
<td>Unknown</td>
<td>Grade 11</td>
<td>Single</td>
<td>Dormitory</td>
</tr>
<tr>
<td>Neesha</td>
<td>Early 40s</td>
<td>Unknown</td>
<td>Grade 10</td>
<td>Single</td>
<td>Dormitory</td>
</tr>
<tr>
<td>Jaana*</td>
<td>Late 20s</td>
<td>Acquired/War</td>
<td>Grade 11</td>
<td>Single</td>
<td>Dormitory</td>
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</tbody>
</table>

**Northern Vocational Community Center (NVCC) Tamil**

<table>
<thead>
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<th>Education</th>
<th>Marriage Status</th>
<th>Living Arrangement</th>
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</thead>
<tbody>
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<td>Chamari</td>
<td>Mid 40s</td>
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<td>Grade 2</td>
<td>Married</td>
<td>With husband</td>
</tr>
<tr>
<td>Lakmini</td>
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<td>Single</td>
<td>With brother</td>
</tr>
<tr>
<td>Gayesha</td>
<td>Late 40s</td>
<td>Developmental/Unknown</td>
<td>Grade 13</td>
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<td>With husband</td>
</tr>
<tr>
<td>Harshani</td>
<td>Early 30s</td>
<td>Developmental/Unknown</td>
<td>Grade 10</td>
<td>Married</td>
<td>With husband</td>
</tr>
<tr>
<td>Shamini</td>
<td>Early 40s</td>
<td>Acquired/Degenerative Disease</td>
<td>Grade 13</td>
<td>Married</td>
<td>With husband</td>
</tr>
<tr>
<td>Roshani*</td>
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<td>Developmental/Blind</td>
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<tr>
<td>Thilini*</td>
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<td>Single</td>
<td>With mother</td>
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<tr>
<td>Kanthi*</td>
<td>Early 60s</td>
<td>Acquired/Unknown</td>
<td>Grade 13</td>
<td>Separated</td>
<td>Head of household</td>
</tr>
</tbody>
</table>
### Appendix C

*List of Women Quoted (page 2 of 3)*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age Range</th>
<th>Disability Etiology</th>
<th>Education</th>
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<th>Living Arrangement</th>
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<td>Nayana</td>
<td>Late 50s</td>
<td>Developmental/Polio</td>
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<td>Head of household</td>
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<tr>
<td>Maheshi*</td>
<td>Mid 40s</td>
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<td>Unknown</td>
<td>Separated</td>
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<tr>
<td>Bimali</td>
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<td>Grade 5</td>
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<td>Acquired/Vehicle Accident</td>
<td>Grade 10</td>
<td>Married</td>
<td>With husband</td>
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<tr>
<td>Lalitha</td>
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<td>Grade 8</td>
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<td>Developmental/Deaf</td>
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</tr>
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<td>Developmental/Unknown</td>
<td>Grade 11</td>
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<td>With mother</td>
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<tr>
<td>Jayanthi*</td>
<td>Late 50s</td>
<td>Developmental/Unknown</td>
<td>Grade 11</td>
<td>Married</td>
<td>With husband</td>
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</table>

<table>
<thead>
<tr>
<th>Pseudonym</th>
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<th>Living Arrangement</th>
</tr>
</thead>
<tbody>
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<td>Vaishnavi*</td>
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<td>Grade 11</td>
<td>Widow</td>
<td>Head of household</td>
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<tr>
<td>Priya*</td>
<td>Early 40s</td>
<td>Acquired/Degenerative Disease</td>
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<td>Married</td>
<td>With husband</td>
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<td>Praveena*</td>
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<td>Yalini*</td>
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<td>Developmental/Unknown</td>
<td>Grade 10</td>
<td>Abandoned</td>
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<tr>
<td>Pushpa*</td>
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<td>Married</td>
<td>With husband</td>
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<tr>
<td>Tabitha*</td>
<td>Late 40s</td>
<td>Developmental/Vehicle Accident</td>
<td>Grade 11</td>
<td>Abandoned</td>
<td>Head of household</td>
</tr>
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</table>
Appendix C

List of Women Quoted (page 3 of 3)

<table>
<thead>
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<th>Pseudonym</th>
<th>Age Range</th>
<th>Disability Etiology</th>
<th>Education</th>
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<th>Living Arrangement</th>
</tr>
</thead>
<tbody>
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<td>Thivya*</td>
<td>Mid 30s</td>
<td>Acquired/War</td>
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<td>Single</td>
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<tr>
<td>Gayathri*</td>
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<td>Widow</td>
<td>Head of household</td>
</tr>
<tr>
<td>Reshika*</td>
<td>Late 30s</td>
<td>Acquired/War</td>
<td>Grade 11</td>
<td>Married</td>
<td>With husband</td>
</tr>
</tbody>
</table>

Note. *Quoted during live interview interpretation only. Developmental is used here to note impairment began from birth or prior to age 13.
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