Chapter 16
Sociocultural Construction of Disability in Sri Lanka: Charity to Rights-based Approach

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Abstract This chapter focuses on exploring the socio-cultural construction of disability in Sri Lanka and its impact on the everyday lives of persons with disability. The analysis is based on an ethnographic study in diverse social settings. As against context-specific characteristics, disability is defined merely as a physical or intellectual impairment of a person from a charity perspective where the ideology of karma plays a crucial role by providing a justification for the existence of inequality among human beings. The construction has adverse effects on all domains of the everyday lives of persons with disabilities. Discrimination against persons with disability originates from family itself that reinforces by other social institutions. Thus, not only the attitudes of lay people but also of service providers suggest no signs of moving from charity to a rights-based approach toward disability. Though Sri Lanka has a National Policy on Disability to promote rights of people with disability, there are huge gaps existing at the level of enforcement. While acknowledging the strengths of social mode, the chapter argues that disability demands an integrated approach toward empowering persons with disabilities and to mobilize the entire society to create an environment with reasonable accommodation for an inclusive society that accepts disability as part of the diversity. The government and civil society organizations have a crucial role in moving forward from a charity perspective to a rights-based approach toward disability.

Conceptualization of Disability in Sri Lanka

Conceptualization of disability varies across different socio-cultural contexts though it is considered as part of the universal human experience. The focus of this qualitative study is to explore the socio-cultural construction of disability in Sri Lanka and its impact on the everyday lives of persons with disabilities. Thus, the present

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ethnographic study attempts to explore the articulation of disability in diverse social settings in Sri Lanka that includes community in a village space; a total institution for persons with disabilities and incurable diseases; a special school for children with disability and higher educational institution. The empirical study adopted qualitative methods and techniques to grasp narratives of persons with disabilities, experience of their everyday life in particular social setting, perceptions and attitudes of parents, close relatives and community members of persons with disabilities, and attitudes and perceptions of service providers on the needs and rights of persons with disabilities. Each social setting has context-specific characteristics while sharing most of the common features in conceptualizing disability and responding toward it.

Disability conceptualizes within the Sri Lankan culture from a charity perspective. The local languages have rather unique vocabulary to distinguish "normal" from "disabled" such as "*arbadita"* – disabled, "*arbaditaya"* – a person with disability and also particular terms attributed to each impairment such as a*ndha* – blind, *golu* – deaf, *bihiri* – hearing difficulty, and so on. These expressions clearly differentiate the "able-body" from the "disabled-body," "normal" from "abnormal" and "ill-being" from the "well-being" where the fixed identity as disabled carries stigma and discrimination. Schools for special education are also named as "school of deaf and blind" that segregates from the ordinary school system in Sri Lanka.

The ideology of "karma" plays a vital role in not only conceptualizing disability but also responding toward persons with disability that promotes charity approach toward disability, justifying the existence of inequality among human beings. In the local context, the concept of karma is constantly used in order to explain the course of disability and many other incurable diseases. The theory of karma is a fundamental doctrine in Buddhism that embodies and reflects many of the ideas that motivate much of the Sri Lankans' attitude toward illness and misfortune and it's implicit in many aspects of the Sri Lankans' understanding. According to the doctrine of karma, individual experience and action is the result of previous volitional acts in their former lives (Rahula 1978:32).

The law of moral causation gives an explanation to understand the cause of inequality that exists among mankind. Why should one person be brought up in the lap of luxury, endowed with fine mental, moral and physical qualities, and another in absolute poverty, steeped in misery, or why should others be congenitally blind, deaf or deformed, and so on. According to Buddhism, this inequality is due not only to heredity, environment, nature and nurture, but also to karma. It is the result of one's own past actions and present doings. Individuals themselves are responsible for their own happiness or unhappiness. Thus, from a Buddhist point of view, our present mental, moral, intellectual and temperamental differences are, for the most part, due to our own actions and tendencies, both past and present (Sayadaw, www.free-ebooks.net/ebook/Insights-Into-Karma). It is the mind that is prominent in committing karma but not the action, not the word. If an individual does any good or bad action with a good or bad intention, the result will follow him/her accordingly. But in further clarification about karma, it says that karma alone is not decisive. There are five elements which can be called as *"niyaama dharma"* *kamma-niyama, beeja-niyama, utu-niyama, citta-niyama, and dhamma-niyama.* So karma is only one factor. These are very important in deciding the karmic effect. Buddhism, however, doesn't prescribe fatalism and people are not supposed to submit themselves to karma alone and they can change karmic effect to a greater extent if they work out. However, in the local social context, disability is seen as an outcome of one's own past actions and present doings where the individual is responsible for his/her own happiness and misery (Sayadaw, www.free-ebooks.net/ebook/Insights-Into-Karma).

The fixed identity of disabled body has become a source of merit for majority of the able-bodied in the society, encouraging them to care for the disabled by simply providing survival needs such as food, clothing, shelter, and so forth while undermining or neglecting most of the civil rights of persons with disabilities as human beings. Thus, the above construction reinforces the identity of the disabled as dependents. The chapter argues that though the charity approach enhances social responsibility toward caring persons with disabilities, it denies equal accesses to education, health, employment, and many other domains of the everyday life of persons with disabilities. The empirical evidence of this study further verified the fact that most of the service providers who deliver various services for persons with disabilities in health, education and social services considered their official task in service delivery as charity while receiving monthly salary as employees. Thus, they assess their role of service delivery as one of the superior positions that allows them to accumulate further merit out of helping persons with disabilities.

Conventional approaches toward disability focus more attention on the challenges faced by persons with disability as an outcome of personal tragedy, locating impairments within the physical body of an individual where medical model plays a dominant role in defining disability, curing ill-health attached to it and rehabilitation of persons with disability. Accordingly, disability is considered as a loss to be compensated rather than a difference to be accommodated by the society (Addlakha 2013). In contrast to the above model, the social model has emerged in order to grasp socio-cultural barriers of disability that originates within the social context rather than identifying it as an individual tragedy (Oliver 1990, 1996). Thus, disability can be defined within the socio-cultural context as a barrier to participation of people with impairments or chronic illnesses arising from an interaction of the impairment or illness with discriminatory attitudes, cultures, policies or institutional practices (Booth 2000). In line with other societies in the world, disability is subjected to stigma and discrimination in Sri Lanka. In the past, there was a trend of hiding the disabled from the society while associating it with supernatural forces that totally excluded them from the mainstream society. However, though perceptions and attitudes toward disability have been slowly changing and persons with disabilities are gradually approaching their rights through self-advocacy movements, the social and physical environments are not adequately prepared with reasonable accommodation to integrate them into the mainstream society. It is evident that only a very limited number of persons with disabilities who come from upper or middle socio-economic backgrounds have been actively involved with disability movements, while the vast majority of lower socio-economic backgrounds remain the same with continuing charity perspective towards disability. Ethnographic reading of this study explores the articulation of disability in diverse social settings while identifying the challenge toward moving forward from charity to a rights-based approach.

Locating Disability in the Locus of a Village

A village is undoubtedly an embodiment of a cultural unit, a moral universe and coherent cultural order connected to the human body. Similarly, the village space is seen as wide open to both well-being and ill-being producing agents. Ethnographic reading of the village implies the fact that not only major impairments but also mild impairments are labeled with fixed identity as disabled that limits participation of persons with disability in most of the domains in their everyday life. The empirical evidence verified the fact that the villagers thoroughly maintain rigid dichotomies between "normal" and "abnormal." Accordingly, a woman with harelip has been labeled as a disabled throughout her life in the village. At the same time a family that includes a number of persons with minor impairments has been labeled "sick family." Participation in most of the activities in the everyday lives of those individuals has been strictly prohibited not due to their functional limitations but due to participation restrictions that are associated with fixed identity as disabled by other members of the family, close relatives, neighbors and the entire community. Pseudonyms are used to present the narratives of persons with disabilities from their voice as follows:

Experiencing Disability in Everyday Life

Karuna was 45 years old at the time she was interviewed. She was born with harelip and continuing with the same. Karuna is the youngest child among nine siblings in her family. As narrated by her mother "immediately after the delivery, I came to know that I had given birth to a disable child. That was the worst day in my life, initially it was very difficult for me to realize as why and how I got a disable child as I have already delivered eight very healthy children. Some of them were born at home without facing any difficulty. However, I prepared my mind with courage to face the situation as it was an outcome of our karma, not only the bad luck of the baby but also due to karma of our entire family."

The delivery took place at the nearest hospital where the baby was kept in the baby-room for few days due to the inability to be breast-fed with the impairment. The mother was informed that she had to stay at the hospital for few days until the baby is released from the hospital.

As Karuna's mother further pointed out "When Karuna was born, the other kids were also too small and therefore I couldn't help leaving her in the hospital for few days to attend the other children. Her father was not willing even to take this disable child home as we already had enough number of children, nevertheless I could not resist my own consciousness anymore and took the baby back home after one week. I was instructed to take the child to children's hospital in Colombo (100 Km away from the village) in a year's time for an operation to remove the impairment, but the domestic task and financial crisis never allowed us to do such a treatment for the new born baby. It was a big issue for the whole village. I struggled a lot to grow up this child even without getting a support from her father. All the other children are married and settled down but we haven't arrange a marriage for this girl because no use of giving a disabled to an outsider."

Along with the fixed identity as a disabled, Karuna was unable to continue her education. At present, the family has no regular income except for the little money that they get from a coconut garden. However, Karuna cultivates some vegetables for consumption and works as a wage laborer at the village. She takes care of her old mother, helps her sisters and brothers and also neighbors when they need her assistance, particularly for caring for the ill members when they are hospitalized, domestic work and agricultural tasks and so on. Though Karuna is an asset not only for her own family but also for the entire community, all of them were compelled to consider Karuna as a liability due to her mild impairment. Karuna's identity as a disabled maintains her position as a dependent though she is the breadwinner and works hard for the survival of the family. Her mother worries a lot about her uncertain future. As she pointed out "who is going to look after this disabled child after my death."

Labor shortage is one of the main problems in the village as there is a trend of the able youth to migrate to seek employment opportunities in the city. In such a context, there is a greater demand for her labor, but she does not receive a fixed wage for the labor, and receives some material supports in return. Evidence suggests that Karuna is exploited due to discriminatory attitudes toward disability both by her own family and the community while misusing her capabilities to the maximum.

The Sick Family in the Village

Wimal is labeled as a disabled due a slight intellectual defect and has physically not grown up to the standards of a "normal" person by the society. He is 40 years, has never gone to school, and is unmarried. Within the village space, the whole family of Wimal is labeled as "sick family" due to some reasons that include premature death of his mother; one of the sisters died due to leukemia; the other sister was separated from her husband; and father has a slight hearing problem. Only the younger brother is considered as normal by the community though he is also marginalized as being a member of the sick family.

At present Wimal lives with one of the relatives who is one of the main land owners in the village. He is responsible for domestic tasks that include bringing water from the well, finding fire wood, cleaning, animal husbandry, agricultural activities and so on. In return, he gets food, clothing and shelter. He doesn't get any salary for his work. Sometimes, he refuses to do certain tasks and there are few occasions when he ran away from this house. But he comes back after few days as he has no other alternatives in the village for survival. The land owner says "We take care of him while providing everything that he needs. Not only that, we will look after his future as well because there is nobody in his family to take that responsibility."

As narrated by the elder sister of Wimal, she was abused by her husband who did not even provide her the basic needs. She was aware that he has an affair with a lady who works at his workplace. Due to a victim of domestic violence, she decided to separate from her husband and came back to the village to live with her parents. However, the villagers compelled to consider the incident as a failure of Wimal's sister as she comes from a sick family and therefore she was unable to have a perfect family life. She has no other choice than a wage labor in the village. Karuna is her best friend; both of them work together and hardly get reasonable salary for their labor. The whole family of Wimal is marginalized in the village space due to the fixed identity as a sick family and they are subjected to exploitation by the able-bodied in the village.

The above construction of disability segregates the able-bodied from the disabled that leads to discrimination and exploitation. As mentioned earlier, disability conceptualizes as a position of dependency and caring for the disabled is considered as a social responsibility while taking it for granted as a source of merit. Both narratives highlight the fact that the above cultural construction of disability provides justification to maintain exploitative relationship between the able and disabled, creating social environment that is advantageous for the able-bodied while marginalizing the opposite.

Locating Disability in a Total Institution

Total institutions for caring for the disabled, those with incurable diseases and many other vulnerable groups were established in Sri Lanka during the British colonial period. This empirical study was conducted in one of the total institutions for the disabled and those with incurable diseases in Colombo district. This home was established in 1889 during the British Colonial Period. The institution is managed by a committee that comprises 16 members including the Government Agent of Colombo District, the Mayor, Director General of Health Services, Director-Social Services, and so forth. At present, the institution has 100 female and 75 male inmates. The medical model has played a great role in organizing the institution which is divided into 14 wards run by a medical staff that includes a matron, number of nursing sisters, and attendants for each ward who are responsible for caring for the disabled. Wards are arranged on gender basis, within that the type of disability and its severity has been taken into consideration. There are a number of criteria for admission. Accordingly, the inmates should be over 18 years and below 55 years old, physically handicapped by birth or accident with incurable nature. After getting admission, the inmates remain in the home for the rest of their lives. There is a great demand to get admission to the institution though a vacancy occurs only on the death of an inmate.

As the administrative officer of the institution pointed out, though the government provides annually 7 million to meet the running cost of this institution it is not sufficient enough for the purpose. However, 98% of the meal requirements are provided by the general public to commemorate their birthdays, wedding and death anniversaries. Institutions for the disabled are particularly attractive for Sri Lankans to celebrate death anniversaries of their close relatives as they consider the space as a source of merit. Most of the donors oblige to provide cash to the institution to cover the meal expenses due to their inability to provide prepared meals. However, the institution provides a regular menu for the inmates without much choice for the inmates and they are discontented. Though some of the inmates suffer from diabetes, they hardly get the diet that is suitable for the condition.

Most of the inmates are not satisfied with their life at the institution where they have lost the sense of "self" while adapting to the institutional setting as the situation goes beyond their control. This is an outcome of total institution as explained by Goffman in his Asylum (1961). The empirical evidence reveals that the institution provides only the minimum survival needs such as food, clothing and shelter for the inmates while neglecting most of their social, emotional and other needs. The space is organized according to the convenience of the service provider. Those with severe mobility impairments have been placed in commode-beds as it is convenient for the service provider, neglecting all the other needs of these people as human beings. Thus, the inmates with mobility challenge face a lot of difficulties as they have to totally depend upon the care given by the caretakers even for minor matters in their everyday life. Most of the inmates are not satisfied with the service that they receive from caregivers, particularly the attendants as they frequently enforce their power on the inmates while not giving sufficient attention to their duties. On the other hand, the attendants too are not satisfied with their employment as primary caregivers because their service is not adequately appreciated by the inmates and also they do not receive sufficient salary though they are involved in a tough task that requires both physical energy and a high level of tolerance to deal with the people with disability. However, the primary caregivers are satisfied with their task as they earn the merit of helping the disabled though they are not receiving sufficient salary for their service as caregivers. Not only the lay people who live in village but also the professionals who provide various services for persons with disability in an institution believe that disability is an outcome of karma and the responsibility of the able-bodied is to take care of them while accumulating merit for the future.

The charity approach encourages society to continue with discriminatory attitudes toward disability while neglecting the needs of persons with disability as human beings. Thus, there is a belief that one gains merit by showing charity toward people who have disability, who are considered to have sinned in the past. Charity is practiced in the belief that the giver is more fortunate than the recipient; it reinforces negative attitudes of inferiority in people who have disability and excludes them from the social mainstream. It is an affront to the self-esteem and dignity of individuals where charity practiced on the basis of sharing with others who have the same rights is to be encouraged. Sri Lanka has developed a National Policy on Disability (2003) in order to promote and protect the rights of people who have disability in the spirits of social justice. However, removing socio-cultural barriers is the main challenge to implement the above policy toward an inclusive society. Not only the lay people but also planners, architectures and different service providers are not sensitive enough to implement the above policy as they perceive disability from a charity perspective that reinforces exclusion and segregation.

Challenge Toward an Inclusive Education for Children with Disability

Sri Lanka has implemented compulsory education ordinance that applies equally to all children including the disabled between the ages of 5–14 years. Initially, more attention was given to provide education to children with disabilities under special schools. The first special school for deaf and blind was started in 1912 in Colombo district during the British colonial period and later on a number of special schools for children with different disabilities were established in other areas of the country. In the early 1970s, the Ministry of Education started increasing educational opportunities for children with disabilities through integration and more recently the emphasis has been given on inclusive education (National Policy on Disability 2003). As a result, children with disability now have an opportunity to obtain their education in government schools either through being included in the ordinary classrooms or in special education units attached to the schools. Though there is a provision in the National Policy to enhance equal opportunities in education, in reality access to inclusive education has become one of the main challenges for children with disability in Sri Lanka like in many other countries in the region due to social, cultural architecture and environmental barriers.

Access to transport facilities is one of the main problems faced by the vast majority of children with disabilities living in rural areas. Most of the children in rural areas have to walk several miles to reach even to the nearest school. At the same time there are no facilities in ordinary schools for children with disabilities such as toilets, wheel chair access, qualified teachers to handle specific issues related to different disabilities, residential facilities and so on. Therefore, most of the children with disabilities have to continue with their education in special schools though they have a right to study in ordinary schools.

Special schools are supported by both the Ministry of Education and the Ministry of Social Services. The teachers' salary is provided by the Ministry of Education and the daily expenses of children are provided by the Ministry of Social Services. Though the amount allocated is not sufficient to cover the daily expenses, nearly 90% of meal requirements and other expenditure are provided by the general public in commemoration of their birthdays, death anniversaries of close relatives etc. like in the total institution that helps the institutions to cover the expenditure. This is one of the reasons that encourage special schools and institutions to continue with the charity approach toward disability.

This empirical study was conducted in one of the special schools for deaf and blind in a remote area. The school was named as "school for deaf and blind" that started in 1978; at present there are 160 students and 25 teachers in this school. The narratives of children who study in this school reveal that special schools are quite convenient for students with disabilities due to some pragmatic factors. The students have an access to Braille and Sing languages with qualified teachers when they study at special school. At the same time, the students are comfortable at special school as they are treated equally with their fellow classmates. Both students and parents highlighted the point that they prefer special schools as they provide residential facilities, otherwise it would be impossible for them to educate their children as most of them come from rural, lower socio-economic backgrounds. Most of the students come from distant places and they go home only during their school vacations.

Special schools are segregated from the ordinary school system that leads to exclusion and discrimination from the mainstream society. Both parents of disabled children and the teachers believe that special school is the best option for disabled children. Some of the parents shared their past experience that they have encountered while their children were studying at ordinary schools with non-disabled students. Accordingly, there were some occasions where disabled students were treated differently by teachers and also some of the parents of non-disabled children did not allow their children to interact with disabled children in class rooms. Some of the children even refused to go to school as they were treated badly. Other than the above motivational factors of parents and children, the teachers at special schools encourage those students to continue their education at special school for their survival. Thus, the evidence suggests that most of the teachers at special schools lack the necessary competency to empower students to face the challenges, they rather socialize them simply to accept the existing disadvantaged position as normal. The evidence of special school also confirmed the fact that the charity approach toward disability is the main barrier for implementing a rights-based approach for inclusive education, though the government and civil society have already initiated some interventions to promote the equal rights that require more radical movements for attitudinal change in the society. Many children who have disability in rural areas are still not starting to go to school and the majority who started schooling are also not going up to the secondary level where gender disparity indicated. Children who have more severe degrees of multiple disability and intellectual disability have no opportunities at all. The education system in both state and private sector lacks expertise and the capacity to deal with these children (National policy on Disability 2003).

The evidence suggests that not only the children with disabilities, their parents and teachers but also the entire society should be mobilized for enhancing inclusive education system in the country. Though the Sri Lankan government has already taken necessary policy decisions toward an inclusive education, huge gaps exist at implementation level due to various social and attitudinal barriers with regard to disability. The following section explores the challenges faced by students with disabilities in higher educational setting.

Articulation of Disability in Higher Educational Setting

Meaningful participation and inclusion in education have become key concepts within the discourse of disability where higher educational institutions can play a significant role in enhancing integrated society with diversity. Entering state universities in Sri Lanka is highly competitive and only a very limited number of students get the opportunity to follow degree programs. State universities have opened the door for disabled students and the enrollment rate of students with disabilities during the last few years has shown an increasing trend (University Grants Commission 2013). However, inclusive education in universities is a greater challenge as academic, architecture, physical and social environments are not ready yet to integrate them with reasonable accommodation in higher educational institutions. According to the information by the University Gants Commission, only 8 out of 16 state universities accept disabled students for their degree programs (UGC 2014). This empirical study was carried out in one of the leading universities in Colombo focusing on understanding everyday experiences of students with disabilities in higher educational setting and the perception and sensitivity of non-disabled students, academic and non-academic staff on inclusive education for students with disability.

The findings suggest that not only the physical infrastructure but also the academic and social environment of the university is not ready yet with reasonable accommodation to integrate the undergraduates to provide an inclusive education. The experience of those students shows that they have very limited options in selecting study streams due to practical limitations. Most of them come from schools in remote areas of the country where there are no facilities to study science subjects. Even when they come to university they have barriers to follow some of the subjects that require more technical assistance. More than 90% of undergraduates with disability are visually impaired and only few students have auditory and mobility impairments. The experience of students with disabilities suggests that they face many difficulties due to both infrastructural and social barriers, particularly when they come to Colombo though it is the capital of the country. The physical barriers include transport difficulties, crossing roads without sound system, lack of wheel chair access, communication challenges and so on. Blind and deaf students have limited access to information as there are no facilities within the university to communicate in Braille or Sing languages. Most of them highlighted that lecturers are not sensitive enough toward them while delivering lectures, giving assignments, releasing results and so forth. They also have to face some difficulties related to administration due to lack of awareness among non-academic staff toward disability. The disabled students appreciated the support that they received from non-disabled students though they do not have enough sensitivity with regard to disability. It is interesting to note that, most of the time the partially blind students support the totally blind students than non-disabled students as they are more sensitive to the issue. Being the majority among disabled undergraduates, visually impaired students have organized themselves to face their challenges. Thus, the evidence reveals that self-advocacy movements among visually impaired undergraduates lead to segregation as they strengthen themselves and are well organized as a group to face specific challenges rather than ignoring interactions with other disabled and non-disabled students. However, few students with auditory and mobility impairments maintain a cordial relationship with non-disabled students while receiving their support for day-to-day activities. Thus, though there are advanced technologies that can be used to enhance accessibility of persons with disability toward knowledge and information, the educators are not well aware of them and also lack enough sensitivity to use them.

Finding employment opportunities for graduates with disabilities is also an issue due to discriminatory attitudes toward disability in the mainstream society. The charity perspective toward disability plays a crucial role even with the higher educational setting like in the above social settings. Evidence suggests that the students with disabilities in higher education need empowerment to face the challenges while mobilizing non-disabled students, academic and non-academic staff to create a favorable environment with reasonable accommodation for inclusive education. The university can play a crucial role in mobilizing not only the university community but also the entire society. However, it has not become a priority in higher education not only due the lack of resources but also due to lack of awareness and sensitivity toward disability.

Challenge to Move from Charity to a Rights-Based Approach

This chapter focuses on exploring the socio-cultural construction of disability in Sri Lanka which is predominantly based on charity perspective. Thus, the chapter highlighted some of the challenges toward shifting from charity perspective to a rights-based approach in order to address issues related to disability. In the Sri Lankan social context, the disabled body has become a source of merit for the non-disabled as it allows them to accumulate further merit while caring for the disabled. The evidence clarifies the fact that not only people with major disabilities but also the persons with mild impairments who have no functional limitations face a challenge due to fixed identity as disabled that has been re-enforced by socially and culturally constructed prejudices and obstacles that are equivalent to social oppression, which is further re-enforced by the doctrine of karma. The charity perspective encourages the society to take care of the persons with disability in the belief that the caregiver is more fortunate than the recipient, reinforces negative attitudes of inferiority in people who have disability and excludes them from the social mainstream. It is an affront to the self-esteem and dignity of individuals. Discrimination against persons with disabilities origins from his/her family to a large extent where they are socialized to acknowledge the disadvantaged position that is gradually reinforced by other social institutions such as religion, education, the economy, welfare system etc.

Though there are government and civil society initiatives to address issues related to disability, the empirical evidence highlights a number of common and context-specific challenges toward moving from a traditional approach based on charity perspective to a rights-based approach toward an inclusive society. The narratives of the locus of the village reveal that the above conceptualization leads persons with even mild impairments into exclusion and exploitation while utilizing their capabilities up to the maximum where there is labor shortage in agriculture. Thus, the findings suggest that the attitudes of not only lay people but also of service providers toward disability have no signs of moving from the charity approach to a rights-based approach. According to the perception of most of the service providers who contributed to this study, existing special schools and institutions for the disabled need to be continued for the well-being of persons with disabilities that requires further efforts to mobilize the society toward a rights-based approach.

The experience of persons with disabilities in the context of higher education where there is an access to inclusive education suggests that the challenges faced by undergraduates with disabilities are not only due to structural and socio-cultural barriers but also due to lack of individual empowerment among the undergraduates with disabilities to fight against discrimination, as they have already been socialized to accept their disadvantaged position due to disability as part of everyday life. The socio-cultural construction of disability has many adverse effects on the everyday lives of people with disability that prevent both their social and physical access to various types of services and opportunities that enhance the quality of life.

How to Move Forward Toward a Disability-Inclusive Society?

Everyday life experience of persons with disabilities in diverse social settings narrated in this chapter clearly highlights some issues that require an urgent responsiveness to move forward toward a disability-inclusive society. The analysis of the present situation of disability inclusion reveals that persons with disabilities are quite marginalized from the mainstream not merely due to charity-based identity formation toward disability but also the shortcomings embedded in law enforcement and poor strategies adopted to implement the National Policy on Disability (2003), and the National Action Plan for Disability (2014) in Sri Lanka. Though there are various programs and activities by different ministries and departments of the government, the NGOs and Civil Society Organizations, the country lacks social and institutional cohesion and a multi-sectorial coordination body to implement interrelated and interdependent interventions from a holistic perspective. The situation leads to a number of drawbacks in the domains of education, health and rehabilitation, work and employment and mainstream enabling environment (Policy Outlines 2015).

The education policy fails to promote inclusive strategies and plans for children with disabilities. The attitudinal environment of school system segregates children with disabilities. Thus, the children with disabilities are left out of the preschool system and the primary and secondary schools are not equipped for students with disabilities where the school dropout rates are high. Children with disabilities are administratively under the special education branch of Ministry of Education and under the non-formal education department. Therefore, children with disabilities are immediately outside the mainstream education. Quality of secondary education limits opportunities for students with disabilities to access higher education.

There are a number of drawbacks in the domain of health and rehabilitation. Inadequate facilities for early detention and intervention; lack of assistive technologies and devices; poor access to health care facilities and specialized services; inadequate facilities and access to rehabilitation and inadequate knowledge and skills for disability work are some of the issues that need urgent interventions to ensure disability inclusion into mainstream.

There are also a number of issues that can be identified in the domain of work and employment. Attitudinal, physical and organizational barriers, inadequate opportunities for job preparation, carrier guidance and counseling, failure of mainstream vocational training system to adequately include youth, inadequate support for self-employment and micro finance, limited opportunities for mainstream employment and failure to provide reasonable accommodation in the work environment and lack of knowledge at the workplace on how to interact with persons with disabilities are some of the crucial issues in the domain of work and employment (Policy Outlines 2015).

The enabling environment has also a number of issues that require urgent attention. The public transport and the built environment are inaccessible. Also there is limited access to public accommodations and telecommunication services. There is no implementation, coordination, monitoring and evaluation mechanism to implement multi-sectorial approach toward disabilities in Sri Lanka. The country also lacks budgetary allocations for disability inclusion activities and lack of partnerships among state, NGOs and private Sector. There is also lack of professional standards and ethical guidelines in disability work.

Sri Lanka has a comprehensive national policy on disability and a national action plan for disability to give effect to the policy with the objective of promoting and protecting human rights of people with disabilities as equal citizens, taking into account the country's social, economic and cultural ethos while at the same time keeping in line with global trends and demands. However, the implementation of this policy has not kept pace with expectations and fails to have a significant impact on inclusion of disability into mainstream development. The drawback is mainly adhered to two fundamental issues. Firstly, the implementation of the national policy on disability is one of the main responsibilities of the Ministry of Social Empowerment and Social Welfare that reinforces charity perspective than a rights-based approach toward disability. Secondly, disability being a multi-ministerial policy, no one ministry can effectively bring other ministries together for disability work as each ministry is concerned with fulfilling the mandate assigned to the concerned ministry, thereby neglecting its interrelated and interdependent dimensions. Filling the gap requires a high level national commission for disability to be placed directly under the office of the executive which may be either the President or the Prime Minister of the country to implement the existing National Policy on Disability and the National Action Plan on Disability in order to promote and protect the rights of people who have disability in the spirits of social justice. Under the new setup of higher level national commission for disability, each ministry can continue the particular mandate with proper coordination where ministry of justice can play a crucial role in strengthening a rights-based approach to ensure disability inclusion in the mainstream development of the country. However, there are huge gaps existing at operational levels that require more social interventions not only to empower the persons with disabilities to exercise their own rights but also to mobilize the entire society to move forward from charity perspective to a rights-based approach to make disability a part of diversity. In order to move forward toward an inclusive society, the findings strongly suggest that strengthening a rights-based approach from top-to-bottom and mobilizing civil society organizations from bottom-to-up should drive simultaneously with appropriate strategies to enhance disability inclusion in the mainstream development. Thus, further research from a multidisciplinary approach is necessary for evidence-based practice as disability studies in Sri Lanka are located at the margin.

Summary

The chapter attempted to explore socio-cultural construction of disability in Sri Lanka and its impact on the everyday lives of persons with disabilities who come from diverse social settings. The study included a community setting, a home for people with disabilities and incurable diseases, a school for special education for children with disabilities and a higher education institution. Disability conceptualizes within the context of Sri Lankan society from a charity perspective. The findings suggest that not only lay people but also professional and different service providers have unfavorable attitudes toward moving from charity perspective to a rights-based approach. While acknowledging the strengths of social mode, the chapter argues that disability demands an integrated approach toward empowering persons with disabilities and also to mobilize the entire society to create an environment with reasonable accommodation for an inclusive society that accepts disability as part of the diversity. Evidence further suggests that there is no sign of emerging strong disability movements in Sri Lanka to fight against the discrimination due to disability as they have been organized in isolation with a narrow focus on addressing specific issues related to a particular disability than organizing them as a powerful group to fight against their rights as human beings with a common goal. However, Sri Lanka has a very comprehensive national policy on disability and national action plan for disability that requires an appropriate mechanisms to implement them. It is recommended to have a higher authority to deal with issues related to disability where the legal aspects should be further strengthened.

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