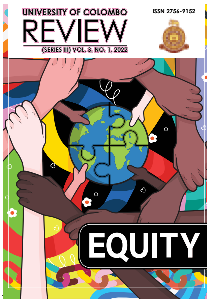
DOI: http://doi.org/10.4038/ucr.v3i1.65



University of Colombo Review (Series III),
Vol. 3, No. 1, 2022

Inclusivity of children with disabilities and downsides of welfare-oriented service delivery system in Sri Lanka with special reference to rural areas in Galle district

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ABSTRACT

Disability is a result of the attitudinal and environmental barriers that hinder persons with impairments from their full and effective participation in society on an equal basis with others. Advocacy movements of persons with disabilities have contributed to changing the perception of disability. Disability-inclusive development has emerged as a method to secure equal rights for persons with disabilities. Social constructionists view the problem of disability as situated within the minds of able-bodied persons: individually as prejudice, and collectively as hostile social attitudes and practices. These negative assumptions of impairments lead to institutional discrimination against persons with disabilities. This article is based on an ethnographic study exploring the lived experience of children with disabilities and their vulnerable families in remote areas of Sri Lanka. It examines the awareness levels of service providers and the recipients on the rights-based approach to disability. The data for this article was gathered by way of qualitative interviews with parents, self-help groups, and service providers. The article describes the shortcomings of the welfare-orientated service delivery system in Sri Lanka and illustrates how the discriminatory practices in education, health, and transport services reinforce the marginalization of children with disabilities. The findings of this article contribute to the limited body of empirical evidence on children with disabilities. Drawing from these findings, the article suggests transforming systems through disability inclusive development.

KEYWORDS:

Children with Disabilities, inclusivity, remote areas in Sri Lanka, lived experience, discriminatory practices.

Suggested Citation: Liyanage, C. (2022). Inclusivity of children with disabilities and downsides of welfare-oriented service delivery system in Sri Lanka with special reference to rural areas in Galle district. *University of Colombo Review* (New Series III), *3*(1), 153 - 172.

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Introduction

Disability is an evolving concept resulting from interactions between persons with impairments, with attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UN Convention on Rights of Persons with Disabilities, CRPD, 2006). People perceive disability and experience it in their daily lives in complex and heterogeneous ways (CBM, 2017). The International Classification of Functioning, Disability, and Health (ICF) defines the term disability based on impairments, activity limitations, and participation restrictions (WHO, 2001). Since the CRPD came into practice, there is further recognition that national governments, regional bodies, and intergovernmental organizations are obliged to ensure that all areas of development, services, and public life are accessible to women, men, girls, and boys with disabilities (CBM, 2017). Disability inclusion is part of a wider movement for inclusive development that strives for the active participation of all people regardless of age, gender, disability, ethnicity, race, social class, religion, sexuality, or any other characteristic (CBM, 2017; UNDP, 2018). Disability inclusive development challenges systemic injustices, exclusive policies, and practices that discriminate against persons with disabilities and seeks to transform such practices (CBM, 2017). The Sustainable Development Goals Agenda 2030 encourages governments to reassess their national inclusive development policies and take necessary actions to enhance systemic inclusivity (UN-SDGs Agenda, 2015). Diverse studies on the lived experience of persons with disabilities reveal that they face excessive difficulties in their everyday life due to obstacles resulting from unfavorable socio-cultural systems and build-environments than from obstacles arising from the impairment itself (CBM, 2017; Halder, and Assaf, 2017; UNDP, 2018). The discrimination that they face contributes to poverty suffered by families with persons with disabilities (CBM, 2017).

Sri Lanka's National Policy on Disability was approved by the Cabinet in 2003. The Cabinet also approved a National Action Plan for Disability in 2014. They seek to promote and protect the human rights of persons with disabilities in line with progressive global standards while taking into account the country's social, economic, and cultural ethos. However, these policies have not been implemented in a manner that would improve the lives of persons with disabilities (Mendis and Perera, 2019; Perera, Kandasamy and Soldatic, 2020; Samararatne and Soldatic, 2015).

Sri Lanka's policy framework for disability work involves four main sectors– health, education, social services, and employment- with social services being the lead agency. Each sector delivers appropriate services independently within its mandate. However, disability inclusivity requires a multi-sectorial, collaborative delivery of services. The National Policy (2003) and the National Action Plan of Disability (2014) provide for such a multi-sectoral framework. Yet, the Ministry of Social Welfare, which is given the authority to implement these policies, takes a welfare-based service delivery approach. Overall, Sri Lanka lacks a multi-ministerial framework to coordinate various services for persons with disabilities.

Several studies on disability in Sri Lanka reveal that persons with disabilities have been discriminated against in various spheres of their everyday life (Campbell, 2011, 2012;

Furuta, 2006, 2009; Hettiarachchi and Das, 2014; Muttiah, Drager, and Connor 2016; Liyanage, 2017; Perera, Kandasamy, and Soldatic, 2020; Samararatne and Soldatic, 2015). But further research is necessary to elucidate the specific experiences of children with disabilities and their families at grass-root levels.

This article is based on an ethnographic study of the lived experience of children with disabilities in an underserved rural setting in Sri Lanka. The article explores issues faced by the children and their families focusing on their access to essential services and community engagement. The following sections describe the conceptual framework of the analysis, study setting, and methodology, focusing on the articulation of the lived experiences of the children with disabilities and how vulnerable families are responding to emerging issues in a remote setting. The article examines the awareness levels of service providers and recipients regarding the rights-based approach toward disability. Scrutinizing their narratives, the article analyses the shortcomings of the welfare-orientated service delivery system in Sri Lanka. The article illustrates how unequal distribution of services reinforces the marginalization of those children living in underserved areas.

Conceptual and theoretical framework for the analysis

"Disability inclusive development" requires disability to be mainstreamed in every aspect of the country's social and economic development through a rights-based approach (UNDP, 2018). In this process, persons with disabilities are to be considered equal citizens with equal rights and equal responsibility to contribute to the country's development. To enjoy equality and equity in their everyday lives, persons with disabilities must enjoy having an equal share of and an equal opportunity to access goods and services (CBM, 2017; UNDP, 2018).

Until the 1960s, the individual or medical model of viewing disability as an individual tragedy played a dominant role (Barnes, 2003; Oliver, 1990, 1996). This contends that mental and bodily impairments are the main cause of the problem experienced by persons with disabilities. Bodily "abnormality" is seen as causing functional limitations which then leads to "disability." Medical experts play a major role as it is their job to offer curative and rehabilitative diagnoses to the problem suffered by persons with disabilities (Barnes, 1991; Giddens & Sutton, 2013, 464-65; Thomas, 2003, 2004). The traditional medical view of disability was that persons with disabilities socially-economically depend on the able-bodied community. This ignores the root causes of disability leading to the systematic exclusion of persons with disabilities from participating in the socio-economic life of the community (Oliver, 1990, 1996; Oliver and Barnes, 1991; Thomas, 2003). Moreover, the medicalization of disability refers to the accumulation of power by the medical professionals and the states resorting to restricting access to state-sponsored welfare systems. Emerging discourse through advocacy movements of persons with disabilities critically challenges the welfare-oriented approach toward disability and argues that the welfare perspective reinforces prejudices against persons with disabilities leaving them in a state of dependency (Shakespeare, 2000, 2004).

Prevailing literature on disability tends to make a range of normative assumptions about the effects of the presence of a child with disabilities on family dynamics. The tendency is to view persons with disabilities as silent receivers of care who are an inevitable burden to their families. It is very rare to hear them articulate their own needs and concerns (Shakespeare, 2004). Oliver argues that partially and essentially an ableist reading of the phenomenon has succeeded in precluding a meaningful evaluation of economic, social, political, and cultural forces which perpetuate disability (Oliver, 1990, 1996, 2012).

The understanding that disability is a social construct requiring social change developed from the 1970s. The approach is informed by the idea that disability is centrally structured by social oppression, inequality, and exclusion (Giddens & Sutton, 2013: 464; Oliver. 1990, 1996, 2012; Thomas, 2003, 2004). The social model explains why social, cultural, and historical barriers have developed against persons with disabilities and stresses the necessity of a materialistic understanding of disability (Barnes, 2003; Giddens & Sutton, 2013: 464; Oliver and Barnes, 1991). Historically, barriers were created against the full participation of persons with disabilities in society during the industrial revolution when they were excluded from the labor market. So they were unable to keep their jobs which became a social problem. The solution for this was institutionalization (Oliver, 1996, 2012). In calling for the removal of social barriers to full participation, the social model allows persons with disabilities to focus on political strategy.

The growing literature on disability reveals that “advocacy movements of persons with disabilities” have contributed greatly to changing perceptions of disability. These movements commenced in the 1890s with the formation of the Deaf Association and the National League of the Blind in Britain (Pagal, 1988). In 1975, people with disabilities formed an umbrella organization called the "Disability Alliance” of Britain adopting a more radical approach toward disability (Finkelstein, 2001; Oliver, 1990, 1996). The goal of evolving organizations since the 1970s was to secure equal rights and remove negative discrimination in all its forms (Davis, 1993). Self-organization and developments at the international level had a significant impact on equal rights during the 1980s. With the above developments, writers with disabilities in Britain and the USA began to challenge individualist medicalized approaches to disability and rehabilitation (Oliver, 2004).

Social constructionists perceive disability as situated within the mind of able-bodied persons, individually as prejudice, and collectively as hostile social attitudes and practices (Oliver, 1990, 1996). While impairment is a medical condition, disability refers to the restriction of activity caused by the contemporary social organization that excludes persons with impairments. The social model focuses on the economic and political considerations which shape contemporary attitudes towards impairments (Finkelstine 1980). Growing literature during the 1980s shows the institutional discrimination against persons with disabilities in education, the workplace, environment, leisure, media, etc. (Oliver, 1990, 1996).

Since the start of this millennium and particularly since the adoption of the United Nations Convention on the Rights of Persons with Disabilities we have gained the understanding that disability is a human rights issue (UN-CRPD, 2006). Disability is a phenomenon that mainstream sociology can no longer ignore within the discipline, similar to the issues relating gender, social class, and sexuality (Oliver, 1996). The growing literature shows the development of a distinct field of interdisciplinary inquiry titled "disability studies" around the world and interest in the subject across social sciences, law and humanities (Albrecht, 2002; Barnes, Oliver, and Barton, 2002). The above discussion provides the theoretical basis for analyzing the lived experiences of children with disabilities and their vulnerable families in underserved-rural areas in Sri Lanka from a sociological perspective.

Setting and methodology

This study upon which this article is based uses a qualitative approach. A qualitative approach provides the researcher with sufficient flexibility to listen to and observe psycho-social, and economic issues faced by families who have a child with disabilities. A series of qualitative interviews were conducted with those families to comprehend their lived experience concerning access to essential services provided by the government, their community engagement and involvement, and activities carried out by self-help groups of persons with disabilities at grass-root levels. Interviewees included service providers who deliver Community Based Rehabilitation (CBR) program, parents/caretakers of children with disabilities, and self-help group members of persons with disabilities (Community Based Organization for PWDs). The study took the natural setting of the child living with disabilities into consideration. Thereby, the researcher facilitated the respondents to build their narratives of lived experiences from their own voices using a phenomenological perspective. The researcher assured the respondents of the confidentiality of their statements. All the respondents gave their consent and voluntarily participated in the study to share their experiences. In this article, the names of respondents and the study setting remain anonymous in line with the ethics requirements.

Setting and study sample

The empirical study was conducted in a Divisional Secretariat in the Galle district. We entered the study setting through a Community Based Organization (CBO) working with persons with disabilities. The CBO has been established with a mandate to empower people with disabilities in the concerned locality through a rights-based approach.

The CBO had strong leadership with widespread membership. It was constituted of several self-help groups among persons with disabilities in adjoining villages. Initially, the CBO adopted a participatory method of identifying persons with disabilities. In expanding its membership, each member of the CBO was given a task to identify a few others with disabilities in their areas and encourage them to join the CBO. The core members of CBO have visited households where persons with disabilities were isolated/hidden in their communities. They have encouraged both persons with disabilities and their family members to join self-help groups. Once they have come out of their households, the CBO has taken necessary actions to integrate them with self-help groups. They carry out income-generating activities, vocational and skill development initiatives, promoting self-employment, awareness-raising, capacity building, and empowerment programs for parents/caretakers of children with disabilities and advocacy for issues related to children with disabilities, etc.

The researcher worked closely with members of the CBO because she served as a resource person to conduct a series of disability awareness-raising programs for the membership and concerned communities. The researcher contacted the participants of the study through the social network of the CBO. A purposive sample was selected for the study that included 20 families of children with disabilities, 28 members of three self-help groups, 3 key informants from the leadership of the concerned CBO, and 13 Service Providers. The service providers included 2 Medical Practitioners, a Nursery Teacher, 2 School Teachers attached to special education units (where the students with disabilities are segregated into a designated classroom) in 2 schools, 5 Social Service Officers (SSOs), a Child Rights Protection Officer, and 2 Administrative Officers in the area.

Methods and techniques of data collection and analysis

A mixed methods approach was used for data collection. Both primary and secondary data sources were used in the analysis. The secondary data sources included relevant books, journal articles, and reports of relevant institutions. The field research was carried out within six months period from March to September 2019. In-depth interviews, case studies, focus group discussions, key informant interviews, and participant observations were used as primary data collection techniques.

The mother was the main caretaker in most of the families interviewed. The researcher conducted in-depth interviews with them by using a guideline that included issues related to the process involved in identifying the child's disability; how the family responded to the situation after diagnosis of the disability; whether the child and the family members were experiencing stigma/discrimination due to disability of the child, access to required services, and psycho-social and economic issues faced by the family due to disability of the child. Four case studies among those families were conducted to get a comprehensive picture of the issues investigated in this article.

The empirical study included three self-help groups of persons with disabilities working under the above-mentioned CBO. The researcher conducted three focus group discussions (FGDs) with 8-10 participants from each self-help group. A nursery teacher and two Social Service Officers (SSOs) assisted the organization of the three FGDs. The researcher also conducted qualitative interviews with key informants and service providers separately. These interviews focused on the knowledge, attitudes, and practices of service providers about a rights-based approach toward disabilities. The organizational capacity of disability movements in the locality, the role of self-help groups, challenges faced by people with disabilities, and related issues were discussed in FGDs and key informant interviews. The researcher was able to participate in several events that were organized by the CBO and relevant Social Service Officers during the fieldwork period. These included a performance of children with disabilities, an informal get-together before Sinhala-Hindu New Year, open fairs organized by self-help groups to sell their products, and a formal function organized by SSOs to celebrate World Disability Day that included several performances by children and adults with disabilities.

Qualitative techniques were used in data analysis. All the in-depth interviews, FGDs, and key informant interviews were conducted in the local language-Sinhala. The researcher recorded the interviews with the consent of respondents and transcribed and translated them from Sinhala to English. The data generated from the mixed-method approach were read repeatedly to identify patterns in data. The researcher carried out the whole process manually. The findings are presented as direct quotes and summary statements. The references remain anonymous.

Experiences of disability in the everyday lives of children with disabilities and their family members

Our qualitative interviews with caregivers of children with disabilities scrutinized how the child's disability impacts their lives as caregivers. In-depth interviews were carried out with mothers of children with disabilities as they play a dominant role in caregiving. In two families, both parents participated in our discussion. In a single-parent family, both the widowed mother of the child and her grandmother shared their experiences.

All respondents who contributed to this empirical study are Sinhala Buddhists. Except for one family, all other families can be identified as vulnerable families based on their disadvantaged socioeconomic backgrounds. Most of them engaged in uncertain livelihood activities. The majority of them were farmers, two were in the clerical service, and others engaged in construction work, carpentry, small business, and daily wage labor. The majority of women in the study sample were housewives who play a dominant role in caregiving not only for the child with disabilities but also for the entire family. Additionally, they were also involved in supplementary income-generating activities to support the family expenditure. There was an exceptional case where both parents of a boy with autism were professionals. The mother of the child is a doctor who voluntarily serves the community as a resource person to educate self-help groups of persons with disabilities and peer parents of children with disabilities on disability rights.

The purposive sample of the empirical study included three children with hearing/speech impairments, 3 visually impaired children, 4 children with Down syndrome, 5 children with autism, 3 children with physical impairments, and 2 children with multiple disabilities. The narratives of those children revealed that most of the families were able to identify the disability of their children while observing their physical appearance, the delayed performance of expected activities, and issues in their behavior. Only a few respondents pointed out that the disabilities of the child were diagnosed by a medical practitioner. Few others noted that nursery/school teachers helped them to identify the disability. 2 parents mentioned that initially they identified disability as a supernatural influence on the child and resorted to religious and ritual healing practices for a long time. It is significant to note that 4 out of 5 children with autism were identified by the nursery teacher and the other one by a medical practitioner. On average, all the children with disabilities have one or two siblings. All respondents explained in detail how they relate to the disability of their children. The narratives reveal that there are similar patterns of caregiving burdens, accessing services including healthcare, education, transportation, and social services, and maintaining relationships within their social networks.

The burden of caregiving for children with disabilities on women

Women play a crucial role in caregiving for children with disabilities. 2 women who were in clerical service have resigned from their employment to take care of the child with disabilities. Most of the women mentioned that they hardly have any leisure time for themselves and that they avoid participating in many events as they were fully occupied with caregiving responsibilities. All the respondents pointed out that they are under severe distress not only due to the burden of caregiving but also due to difficulties in accessing relevant services due to the discriminatory attitudes of service providers. Most of the caretakers have restricted relationships with some relatives/neighbors due to their negative responses to the child with disabilities. One of the respondents described her experience in the following way;

> “I never allow my child to play with other children because they discriminate against my child. I think nobody in this village can understand the nature of the disability unless they have a child with a disability. We face a lot of difficulties everywhere. Once someone physically harassed my child when I was taking her back from the nursery. Since the bus was overcrowded, I came to know about this after she started crying non-stop. I got annoyed and shouted like a madwoman on the bus” (Mother of a girl child with Down syndrome).

Some narratives reveal that parents attempted to hide their children with disabilities as it was extremely difficult for them to bear the stigma associated with disability. In our in-depth interviews, 2 respondents mentioned how most of the children with disabilities who were hiding in the households have come out due to the interventions by the CBO. The members of self-help groups have visited them and encouraged them to direct the disabled child to nursery/school/vocational training centers. They have also invited these families to join their self-help groups for further assistance. One of the respondents noted the following;

> “After joining the self-help group I was able to realize that it was not a problem only for us but a common issue for most of the parents who have a child with a disability” (Mother of a child with Autism).

All the respondents who contributed to the study mentioned that they are happy to participate in self-help group meetings as it provides an opportunity for them to share their experiences with others who can genuinely understand such issues and even provide the necessary assistance to overcome some of their difficulties. This is especially important as they have limited their association with relatives and neighbors due to negative responses about the disability of the child. In such situations, they have been isolated. In this context involvement in self-help groups provides them with networking with others who can understand their issues and receive emotional support. Most of the caregivers have acknowledged the assistance that they receive from other family members in caregiving for the child with disabilities. However, the evidence reveals that the women are compelled to bear a comparatively heavy burden on this matter. The narratives further reveal that the disability of a child in a family has negative consequences on siblings because they receive comparatively less attention and care from parents. Sometimes they are harassed by the child with disabilities. Moreover, they are affected emotionally by the social stigma toward the disability of their brother/sister.

Issues related to getting access to essential services

Empirical evidence reveals that children with disabilities and their family members face a lot of difficulties in accessing various services including public transport, health, and education. All the respondents pointed out the difficulties they face in accessing public transport services. As most of them are living in remote areas, they have to come to the nearest city to access most of the essential services. However, only a few buses run up and down from the village to town. These buses are also overcrowded during peak times when children go to school and return home. Only a few families have access to their own transport facilities. Very few can afford private transport facilities such as trishaws or school transport services on a regular basis. As the respondents pointed out in focus group discussions, the majority who use public transport services face numerous problems especially when they take their children with disabilities to school/nursery. These families face issues of verbal/ physical harassment in overcrowded buses, difficulties in securing a seat for the child with disabilities, and aggressive behavior of children with disabilities. Most of the parents attempt to hire a trishaw to overcome such difficulties which compels them to bear an additional expenditure for transportation. Limitations in access to transport services become a further barrier to accessing health, education, and other services and also prevent these families from participating in many other events.

In accessing healthcare services, most of the respondents mentioned that they are compelled to wait in long queues with the child with disabilities and that the healthcare providers did not provide sufficient attention to their children. The respondents also highlight the lack of information about the child's disability and the treatment plans. For some services, they are compelled to access the private sector or have to be on the waiting list for a long time to receive the recommended treatment. In focus group discussions, the participants shared experiences of verbal abuse they faced when interacting with healthcare providers.

The empirical evidence reveals that children with disabilities and their parents face the most difficulties in getting access to education. As mentioned earlier, our study sample involved twenty disabled children who were under 18 years old. Out of these students 3 have already dropped out of the school, 12 students were attached to special education units, 2 children are studying in normal classrooms and 3 students are in the nursery education. The findings of both in-depth interviews and focus group discussions with parents/caregivers reveal that they face numerous issues concerning the education of children with disabilities. Some schools rejected the integration of children with disabilities into mainstream classrooms. Teachers paid less attention to children with disabilities. These children faced harassment and neglect in schools by children without disabilities. They were excluded from many activities in the school. The Special Education Unit of the school is allocated an isolated place in a corner of the school. Consequently, children with disabilities were segregated from other children. There were long waiting periods to get an opportunity in special education units and the special education units lacked qualified teachers. Few participants pointed out that the teachers who are attached to the special education unit face difficulties due to the problematic behaviour of their children with disabilities. A child with Autism, who was recently enrolled in a special education unit, has refused to attend school. According to observations of parents, this was because the learning environment of the school was not favorable for the child. The parents have made arrangements for him to continue the nursery education until they find an appropriate solution. According to the nursery teacher,

> "This child seeks more attention and he expects an opportunity to deliver a speech every day immediately after nursery starts. He comes prepared for this and also does it very well. Allowing him to perform this activity would be sufficient for me to guide him the whole day" (This nursery teacher has received training on disability issues).

Therefore, when the child started schooling, the teachers' lack of competency to adjust according to the needs of the child affected his enthusiasm to learn. When the parents informed the teacher about the child's disability and previous experience at nursery, the teacher blamed the parents for "spoiling" the child (Allowing the child to do what he prefers/needs instead of parents attempting to control and correct his behavior). This incident distressed parents severely, particularly the mother who was receiving counseling for her depression. The child is studying happily at the nursery for the moment. The teacher conducts additional classes for him after finishing the nursery until the matter is sorted out by the parents.

The experiences of a few other caregivers confirm that the performance of the above nursery teacher is very effective for children with disabilities. The service users are very satisfied with her performance and children travel even from a distance to attend her nursery. This is because she understands the needs of children with disabilities and arranges the learning environment accordingly. Parents of those children voluntarily assist the nursery teacher in handling a large number of children. As explained by the nursery teacher, her popularity may be mainly due to in-service training that she received on disabilities which were organized by Fridsro, an NGO working on disability rights. This NGO supports the government to implement its Community Based Rehabilitation (CBR) program. In that training, she learned how to understand a child with a disability, their needs, and the best methods for dealing with their issues. She attempts to apply the knowledge she has gained and the skills she has developed. She stated that, "Not only do parents appreciate my performance, but I also get financial benefits too as more children come to get my service."

The parents/caretakers and members of self-help groups at FGDs mentioned that there were some occasions when the school refused to accommodate their children with disabilities not only in the normal classrooms but also in the special education unit in the nearest school. On one occasion when the school administration refused to accommodate children with disabilities into the special education unit at the nearest school, the parents and self-help groups collectively responded by preparing to make a complaint to the Department of Education and the Human Rights Commission. When the school administration came to know about it, they took immediate action to accommodate those children. Self-help groups in the area provide ardent support to challenge such discriminatory practices. However, the children in special education units undergo exclusion and experience physical and mental harassment from teachers and children without disabilities. As participants at FGDs pointed out,

> "Very often the teachers in charge lock the room with children with disabilities and go out. Nobody knows even if something happens inside the room. We complained several times but this practice is continuing. No use of telling them as they're not interested even to listen to us" (FGDs with Self-help groups).

Adding to the discussion a mother of a child with a disability pointed out that,

> "The teacher in the special education unit should understand the nature of children with disabilities. One day she hit my child even without washing her hand after eating (ඉඳුල් අතින් ගහලා). After this incident, my child refused to go to school for a long time. We struggled a lot to prepare his mind to send him back to the school" (Mother of a child with hearing impairment).

Participants of one of the FGDs further highlighted that their children are bullied by other children. Children with disabilities are emotionally harassed through the use of bad words, provoking them to become aggressive and commit physically harmful acts. Sharing her experience, a caregiver pointed out that recently her child was pushed into a garbage dumping site by a group of children without disabilities. However, the teacher has not taken any action when this matter was brought to her attention. Most of the parents were not satisfied with the quality of education that their children received from the special education unit. The students showed no progress and the parents were disappointed, feeling that they wasted both time and money in sending the child to school. While sharing her experience a participant pointed out that,

> "The teacher who was trained on special education was assigned to teach the grade five normal class to prepare those students for grade five competitive exam as this teacher had the competency to teach attractively. This was despite there being a shortage of trained teachers for the special education unit." (FGDs with self-help groups).

Therefore, the school environment with structural and attitudinal barriers reinforces the segregation of children with disabilities in education. School enrollment of children with disabilities in primary education is satisfactory. However, focus group discussions with self-help groups reveal that many children with disabilities in their locality dropped out at the secondary level. Reasons for this included a discouraging environment at school, socio-economic difficulties faced by parents to support their education, and the unsatisfactory educational performance of the children. The lived experiences reveal that children with disabilities have been excluded and discriminated against in various ways in accessing education resulting in a huge amount of emotional distress among parents. The network of self-help groups plays a crucial role in supporting families to face some of these issues collectively. However, the evidence suggests that the capacity of self-help groups to engage in effective advocacy is limited.

As mentioned earlier, the CBR program operates at the grass-root level to assist self-help groups of persons with disabilities. In practice, the CBR program predominantly focuses on providing material support for vulnerable individuals than empowering them. The CBR program lacks appropriate strategies to strengthen the capacity of self-help groups. The narratives reveal that Non-Governmental Organizations (NGOs) working for disability have implemented various interventions in the study setting to promote the rights of persons with disabilities. The interventions included disability awareness-raising program for self-help groups and relevant service providers, capacity building among office bearers of self-help groups, awareness-raising on gender and reproductive health concerns, and training program on livelihood activities for persons with disabilities and their family members. Though these interventions show some improvements in their lives, their impact is haphazard due to the absence of follow-up strategies, financial issues, and lack of access to disability counseling services.

Knowledge, attitudes, and practice of service providers regarding disability

The researcher assessed the service providers' knowledge, attitudes, and practices in providing services for people with disabilities while conducting interviews. The researcher also reviewed the knowledge of service providers about the rights of people with disabilities and the discourse on disability inclusive development.

The findings reveal that all the service providers believe that their service/s should be delivered without any discrimination based on disabilities. The 2 administrative officers who participated in the study on which this article is based mentioned that they have already taken necessary steps to improve the accessibility of their services for persons with disabilities. They listed instances where the buildings have been refurbished according to the needs of people with disabilities. For example, ramps were installed at the entrance of the building and the office of the social service staff was shifted to the ground floor. They pointed out that the Social Service Officers (SSOs) serve people at community levels. They were of the view that the SSOs implemented several activities to address social issues associated with disability. The administrative officers further pointed out that they provide financial assistance for needy people to overcome their financial difficulties. They also emphasized that SSOs are responsible for implementing Community Based Rehabilitation (CBR) program.

Compared with other service providers, the SSOs work closely with people with disabilities. Some of their interventions have targeted children with disabilities. These included get-to-gather events for children with disabilities during New Year/ Christmas break, events in celebration of the World Disability Day, and forums to provide referrals for vocational training programs for school dropouts. They also collaborate with self-help groups to conduct their activities at community levels.

However, they hardly focus on innovative interventions that empower persons with disabilities by promoting their rights. As mentioned earlier, children with disabilities face a lot of issues in schools. However, there is no evidence to suggest that either SSOs or the Child Rights Promotion Officer are involved in these instances to protect the rights of children with disabilities. Thus, their interventions are simply limited to transferring the welfare agenda of the state from top to the bottom while reinforcing the dependency of persons with disabilities on welfare benefits.

The SSOs and the Child Rights Protection Officer claim that they were motivated to apply the rights-based approach after completing an in-service program on disabilities conducted by Fridsro. However, they state that the structural barriers and attitudes of other service providers prevent them from implementing innovative strategies to include people with disabilities in social and economic development. One of the SSOs reflected on her experiences in the following way,

> "I coordinated a training program with the Agriculture Department for a group of girls with Down syndrome. There was a condition for the participants to start a home garden after completing the training. All the children who joined the training completed the program and started a home garden on their own. The parents were very happy with the improvements of the children due to the training. We also noticed that it was a good project for these children. However, the responsible officers evaluated it negatively. They were not satisfied with the outcome as it was not up to their standard. Therefore, they recommended that the project be discontinued." (Officer of Social Services).

Thus, the funds are usually allocated to repeat only traditional programmes such as home gardening and handicrafts. Hardly any allocations are made for innovative programs that promote the rights-based approach in service provision.

The 2 teachers who shared their experience in serving special education units stated that working in a special education unit is very difficult as each child has specific needs. Both teachers were trained in delivering special education. They hardly use the term "children with disabilities/ disabled children" but very often they use the terms "differently able" or "children with special needs". Both of them were of the opinion that there should be a special arrangement for "children with special needs" to prevent them from being harassed by other children. They also assumed that it would be harmful to other children if children with disabilities are integrated into the normal classroom. They have heard about inclusive education. However, both teachers did not seem to think that the rights of the children with disabilities are violated by segregating them from children without disabilities in the education process. Though they are aware of the difficulties faced by parents of these children, they did not know how to assist them other than expressing their sympathy. In contrast, the nursery teacher mentioned earlier was better equipped to assist both the children with disabilities and parents because of the training she received through the awareness program. Her performance highlights the importance of effective disability awareness-raising programs for service providers to deliver better services for children with disabilities.

Medical Practitioners consider disability as a medical problem and that the healthcare providers could solve most of the related problems. One of the practitioners pointed out that in most cases, the parents take the child to the hospital when the problem is serious and suggests that interventions are required to educate them to seek early treatment. However, the other medical practitioner disagreed with this view and explained that disability is not such a simple issue. She states that because she is also a parent of a child with Autism, she is aware that there are several drawbacks in the healthcare delivery system in this regard.

> "I think even the doctors don't have sufficient knowledge to identify a child with a disability. All the disabilities are not in visible form. As a young mother I myself couldn't understand that my child is autistic until the child was 4 years old though I am a doctor. I observed that his activities are delayed than a normal baby's but never thought that he is autistic. I learned more about disability only after I became a parent of a child with disabilities." (Medical practitioner with an autistic child).

Drawing from her personal experience, she claims that disability is severely neglected by the healthcare delivery system and also in the curricula at Medical Faculties. The rural hospitals lack some of the essential facilities to diagnose children with disabilities. She also noted that parents should be sufficiently educated by medical practitioners on the relevant disability and treatment options that are available. She too views disability as a medical problem. But she acknowledges that disability is associated with many psychological and social issues. Therefore, she considers a collaborative decision-making process between parents and healthcare providers to be important. The evidence suggests that one medical practitioner is more sensitive to disability-related issues because of her personal experience of being a parent of a child with disabilities. The other example suggests that medical practitioners do not have sufficient knowledge of the multidimensional nature of the disability.

The above empirical evidence of different service providers reveals that there are gaps in their service delivery to persons with disabilities. Most of the services reflect a top to bottom approach and adopt universal distributive mechanisms which fail to accommodate either the need-based or the rights-based approaches for service delivery.

Discussion and conclusion

Our empirical investigation focuses on identifying issues that children with disabilities and their families face in accessing essential services. The medical model of disability described earlier plays a dominant role in Sri Lanka though the social model of disability is slowly gaining recognition. In practice, the focus is still on changing the individual rather than on changing the structural and social environment. Community-based Rehabilitation (CBR) was developed to remove barriers through social change but was often misinterpreted and implemented by rehabilitation professionals who see the issues through the medical model (Mendis, 2014). The greatest benefit of the social model is in its recognition of the voice of persons with disabilities (Oliver, 1990, 1996). The current situation reveals that though Sri Lanka has a comprehensive National Policy on Disability its implementation has been weak. Therefore, persons with disabilities continue to face marginalization in the areas of health and rehabilitation, education, work and employment, mainstreaming and enabling environment, and social and institutional cohesion (Policy Outlines, 2015). Thus, disability studies as a field itself remain underdeveloped in Sri Lanka (Campbell, 2011).

The empirical evidence reveals that there are weaknesses in delivering essential services such as health and education for persons with disabilities. Inadequate facilities for early detection and intervention, lack of assistive technologies and devices, poor access to health care facilities and specialized services, inadequate access to rehabilitation, and inadequate competency for disability work are some limitations in the health care delivery system.

Meanwhile, the education policy fails to promote inclusive strategies and plans for children with disabilities. The school system segregates children with disabilities. Primary and secondary schools are not equipped for students with disabilities leading to high school dropout rates. The children with disabilities are administratively under the special education branch of the Ministry of Education and the non-formal education department. Therefore, children with disabilities are outside of mainstream education (Furuta, 2009; Mendis, 2014; Policy Outlines, 2015). A study that analyzed gaps in special education services in three provinces of Sri Lanka has identified the need for Speech and Language Therapists to work in schools (Muttiah, Drager, and Connor 2016). Some other studies too confirm that the barriers to accessing special education include the limited number of rural schools having special education units, the refusal by administrators to admit children with disabilities to schools, shortages of qualified teachers, and the lack of awareness among parents regarding educational facilities (Furuta 2006; Furuta 2009).

Currently, there are four educational options for children with disabilities in Sri Lanka: specialized schools, special education units within regular education schools, inclusive regular schools, and special resource centers attached to regular education schools (Hettiarachchi and Das, 2014). However, the findings stated in this article reveal that special education units in regular schools are the only option available for children with disabilities in rural areas. Thus, the children with disabilities face difficulties in enrolling in the nearest school, and those who have enrolled face participation restrictions in many activities in schools.

Evidence reveals that the parents have organized themselves as self-help groups to fight against discriminatory practices experienced by their children with disabilities in education at the grass-root level. They have gained some positive outcomes through collective efforts. However, their capacity is inadequate to challenge the authority of service providers and their discriminatory practices. The welfare-based public service delivery system operates through a system of bureaucrats who lack both sufficient knowledge and favorable attitudes to work with persons with disabilities as equal citizens. The charity perspective toward disability plays a dominant role in Sri Lanka (Liyanage, 2017). The findings in this article confirm that service providers' sympathetic viewpoint of disability reinforces discriminatory practices in their service delivery process rather than considering persons with disabilities as equal citizens.

Investigating the relationship between policy at the national level and practice at the community level in Sri Lanka's CBR program, Masateru notes that the program's capacity to develop human resources is limited. He identifies several gaps between the planned policy and the conducted practices (Masateru, 2019). The findings of this article confirm that the CBR program lacks appropriate strategies to empower persons with disabilities. Self-help groups have been formed to implement the CBR programme. The structure of the CBR programme aims to incorporate the voices of persons with disabilities through self-help groups from community and district levels up to the national level in designing and implementing required interventions. However, in practice, the authorities hardly incorporate the views of persons with disabilities into the process. Instead, they attempt to transfer pre-designed interventions from top-to-bottom through their bureaucratic system on the basis that persons with disabilities are passive recipients of their programs. The findings confirm that the service delivery system lacks appropriate strategies to include persons with disabilities and their families to promote disability inclusive development.

The NGOs working for the promotion of disability rights grass-root level have chosen human resource development as their main method of intervention. However, these interventions have not continued due to financial issues, lack of coordination, and lack of effective follow-up mechanisms. While the children's family functions as a collective group to face the challenge, the mother as the main caregiver undertakes a sacrifice by voluntarily removing herself from participating in other domains. She also faces excessive emotional distress. They are the most vulnerable members of society suffering silently. The finding suggests that women need psychosocial counseling and support services including financial assistance for self-employment that they could engage in while careering for a child with disabilities.

The findings confirm that public transport and the built environment remain inaccessible to persons with disabilities. These persons from rural communities face further difficulties with insufficient physical infrastructure and transport facilities. The negative perception of disabilities among service providers perpetuates discriminatory practices. The experience of CBO reveals that community-based organizations have the potential to empower persons with disabilities. It also provides a forum for persons with disabilities and their family members/caretakers to share their experiences and respond collectively to discriminatory practices. However, the sustainability of such organizations depends on the availability of financial and human resources from outside the community. The organization lacks the financial capacity to function effectively with planned activities focusing on the empowerment of persons with disabilities.

Moreover, there are no mechanisms to coordinate the diverse interventions of the Government, Non- Governmental, and Civil Society Organizations. The state implements interventions predominantly based on a welfare perspective reinforcing the dependency of persons with disabilities on welfare services. The NGOs on the other hand work for the empowerment of people with disabilities. Meanwhile, self-help groups of persons with disabilities attempt to address burning issues in their everyday life. The evidence suggests that disability movements in Sri Lanka may require time to determine their common goals and set agendas to move forward with the rights-based approach.

Children with disabilities face greater challenges due to unfavorable socio-cultural and physical environments. The empirical study on which this article is based explores the drawbacks of welfare-based service provision focusing on children with disabilities and highlights the challenges in transforming the system towards a rights-based approach. The findings suggest the need for an authority at the national level that has the competency to go beyond the mandate of the Ministry of Social Welfare. This is crucial to coordinate the multi-sectorial and multi-ministerial approach required for the effective implementation of the National Policy and the National Action Plan on disability policy which would in turn promote disability inclusive development. Further studies are required to analyze gaps in the implementation of the CBR program and identify appropriate strategies for disability inclusivity. As mentioned earlier, this article is limited to exploring issues faced by the selected group of children with disabilities and their vulnerable families in accessing essential services. Studies at the national level would be useful to design appropriate interventions to minimize gaps in service provision for children with disabilities in Sri Lanka.

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Acknowledgment

The author acknowledges the valuable contribution of Mr. Kumara Deshapriya, leader of self-help groups, and all respondents who shared their lived experiences of disability to develop this article. The author acknowledges the assistance given by Thiran Liyanage during fieldwork and writing the article.