

PERSPECTIVES IN REHABILITATION

Disability studies in Sri Lanka: priorities for action

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Abstract

Purpose: To review the published literature relating to disability in Sri Lanka, identify research gaps and inform priorities for action. **Methods:** A narrative literature review was undertaken and relevant articles extracted using electronic databases such as Medline and PubMed. The available literature was examined in relation to the nine key recommendations of the *World Report on Disability*. **Results:** Over the past 30 years, published disability research in Sri Lanka has primarily focussed on mental health, visual impairment and healthcare delivery. Significant gaps were apparent in evidence relating to the status and services for people with intellectual disability, policies and their impact, provider attitudes, barriers to education and employment, health workforce training and access to healthcare. **Conclusions:** While published studies provide insights on several dimensions of disability, there are important research gaps pointing to unmet needs that require attention to support the health and wellbeing of people living with disability in Sri Lanka. To address these gaps, it is imperative that a critical mass of multi-disciplinary researchers including people living with disabilities collaborate on a strategic program of research using effective participatory approaches that engage all sectors and communities relevant to uphold the rights of people living with disability.

Keywords

Developing country, health priorities, Sri Lanka

History

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► Implications for Rehabilitation

- All nine key recommendations in the *World Report on Disability* are highly pertinent to the needs and status of people living with disabilities in Sri Lanka.
- Significant gaps in research on disability-related health issues exist and warrant more focussed attention by researchers, funders and policy makers.
- It is imperative that national stakeholders including the Ministries of Health and Social Welfare, organisations representing people living with disability and related advocacy groups, work collaboratively to identify and implement a research strategy that would better inform disability policies and programmes that have access and equity as core principles.
- Implementation of a national disability survey by the Department of Census and Statistics, will help prioritize disability research in the country.

Introduction

The *World Report on Disability*, released by the World Health Organization (WHO) in June 2011 provides a comprehensive view of the current global knowledge on disability, identifying disability both as a human rights issue grounded in the values of the Convention of the Rights of Persons with Disabilities, and a development issue given the bidirectional link to poverty [1]. Endorsing the recommendations of the World Report the 66th World Health Assembly held in May 2013 adopted a resolution calling for better health care for people with disabilities [2].

The chapters of the *Report* on general health care, rehabilitation, assistance and support, enabling environments, education and, work and employment summarize available global data and provide a strong case for action by identifying gaps and discussing how to address each. Based on the best available information on disability, the report succinctly provides recommendations for action at national and international levels. The concluding chapter on recommendations for moving forward provides nine categories of recommendations that cover multiple domains. The last recommendation, to strengthen and support research on disability, stresses the need for further research, with focussed investments in building a critical mass of trained researchers on disability, particularly in low- and middle-income countries (LMICs). The *Report* challenges all nations to take stock of their current status and engage researchers in disability studies in an effort to increase public understanding, inform disability policy and programmes, and efficiently allocate resources.

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Sri Lanka is a lower-middle income country with GDP per capita of US\$ 2375 in 2010 and a population of approximately 20 million. Notable strengths of the Sri Lankan healthcare system in relation to many other countries of a similar GDP per capita include expressed visions of equity, relatively high levels of system efficiency (in terms of costs for government and households) and positive health outcomes, particularly including low infant mortality rates and relatively high life expectancy [3]. The distribution of all health services in Sri Lanka are reported as equitable with a pro-poor distribution of outpatient care as measured by use [4] and most people living within 5–10 km of a healthcare facility [5].

Notwithstanding these apparent successes, the incidence of disability in Sri Lanka has increased from 1981 to 2001 due to population ageing and the civil war [6]. The 2001 census data provides information on disability at a national level, except the districts in the North and East of the country, due to the civil war at the time [7]. Approximately 300 000 people reported a disability in the 2001 census. The conditions with the highest prevalence estimates per 10 000 population were impairment related to vision (41.0), hearing or speaking (43.5), hands (28.5), legs (7.9); other disabilities relating to physical (53.7) and mental health (40.9). These figures are likely to be underestimates given the problems associated with how disability was defined and perceived at the time of the census (a person who was unable or limited in carrying out activities that he or she can do due to congenital or long-term physical/mental disabilities) and the escalation and end of the civil war in 2009. More recent estimates suggest that over 1.4 million people (7% of total population) live with some form of disability in Sri Lanka [8]. WHO estimates 15% of the world's population to be living with some form of disability, an increase from previous estimates of 10% in the 1970s [1].

The status of disability in Sri Lanka in relation to poverty reduction [9], training and employment [10,11] and in the elderly [6,12] are discussed in reports published by various non-governmental organizations. Alongside these, some studies have also examined aspects of the disability and health relationship. This article reviews published reports on disability-related health research in Sri Lanka to identify the major areas of research focus to date, apparent needs and gaps, and strategies for moving forward, based on recommendations of the *World Report on Disability*.

Methods

Articles for this review were identified by searches of Medline and PubMed. Articles from Sri Lanka published in the last 30 years (1982–2012) were included. Search terms included congenital, developmental, sensory, physical and injury-related disability, autism or autism spectrum disorder, visual impairment or blindness or cataract or glaucoma, hearing impairment or deafness, burns, elderly disablement, cerebrovascular disease or stroke, mental health or psychiatric disorders, schizophrenia, depression, dementia, Alzheimer's disease, alcohol or drug dependence or abuse, health care delivery and rehabilitation.

Although searches were not restricted by language or publication status, disability studies in domains other than health were not included. As this was not a systematic review grey literature was not examined. No attempt was made to examine the quality of published studies as this was outside the scope of the review. Selected studies were categorized depending on their primary area of focus into (a) congenital and developmental disability; (b) sensory disability; (c) physical disability including injury-related disability; (d) elderly disablement; (e) mental disability, alcohol and drug dependence; (f) disability-related health care delivery; or (g) rehabilitation.

Major areas of research focus

Overall 69 papers were identified and examined. The number of studies examined in each selection category are summarized in Table 1. Most studies were population-based cross-sectional studies ($n=32$) or hospital-based case series ($n=16$). Seven studies were cross-sectional studies based in an institution (school for visually impaired people, rehabilitation centre or medical facility).

There were six studies providing a descriptive analysis of congenital heart disease [13], cleft lip and palate [14–16], visual impairment due to abnormalities of the globe (part of a multi-country study) [17] and autism [18]. Studies on sensory disability included 10 studies based on visual disability alone [19–27] and one on uptake and use of hearing aids among children [28]. Four studies determined prevalence of cataract [22,23], macular degeneration [24] and angle closure [25], and two examined the prevalence of a combination of cataract, glaucoma, refractive errors and macular degeneration [26,27]. Three studies were among children attending a blind school and determined cause of vision loss [19,20] and criteria for entrance to school and educational attainment [21]. Two further studies conducted among the elderly determined pattern of disablement and reported findings in relation to impaired vision [29] and hearing [30].

Physical disability was the focus of study in landmine victims [31], army veterans with amputations [32] and people with lymphoedema [33]. One study reported on the incidence of injury-related disability [34] and two on burns [35,36]. Two studies reported on stroke, including one on risk factors in those aged less than 45 years [37].

Disablement among the elderly (other than pure sensory disabilities and mental disorders) was reported in six studies; one hospital- [29] and five population-based studies [30,38–41]. There were 17 studies related to mental health which included prevalence studies on dementia [42] and schizophrenia [43,44], depression [45–49], psychological stresses of war [50–53], natural disasters [54–56], family violence [57] and snake bite [58]. A further five studies reported on alcohol and drug use [59–63].

Disability-related health care delivery was a focus of study in 14 papers, four papers each on stroke care [64–66] and mental health care [67–70], two each on speech therapy [71,72] and limb care [33,73], one each on cataract surgical coverage [23] and the use of health workers to identify mild-moderate disability in young children [74]. One study focussed primarily on rehabilitation of alcohol dependent males [75] and another developed and tested the integration of community-based rehabilitation and mental health and development services [76].

This study addresses a critical gap in knowledge regarding the context-specific evidence base on disability-related health research that a developing country can draw on. The major limitation of this study is that it was not designed to be an exhaustive review of studies that covered all domains of disability,

Table 1. Papers examined on health aspects of disability in Sri Lanka.

Selection category	Number (%) of papers
1. Congenital and developmental disability	6 (8.6)
2. Sensory disability	11 (15.9)
3. Physical disability (including injury-related)	8 (11.5)
4. Elderly disablement	6 (8.6)
5. Mental disability, alcohol and drug dependence and problems of use	22 (31.9)
6. Disability-related health care delivery	14 (20.3)
7. Rehabilitation	2 (2.9)
Total	69 (100.0)

particularly given the challenges of identifying studies that may only be in report or monograph format. The review was also not designed to generate information on the totality of the disability burden in the country, especially including disabilities as a consequence of other health conditions such as diabetes and ischemic heart disease. Rather, the intention of this paper was to provide a snapshot of the general areas of focus in disability-related health research to date as a starting point for further analysis and priorities for action.

Although speculative, the lack of coverage and focus of some aspects of disability in the studies examined may well be due to the varying perceptions and concepts of disability, the lack of trained researchers on disability and limited funding opportunities. The first chapter of the *World Report on Disability* introduces the complexities surrounding the “evolving concept” of disability, the extent to which this is addressed by the International Classification of Functioning, Disability and Health (ICF) framework and the relationship between disability and the environment [1].

Recommendations in the context of the World Report on Disability

The authors of published studies in Sri Lanka make wide ranging recommendations based on their findings and these are examined in the context of the nine cross cutting recommendations made in the *World Report*. This analysis particularly focuses on recommendations in published commentaries and reports that relate to health care delivery in Sri Lanka.

Enabling access to all mainstream systems and services

The *World Report's* first recommendation is to enable people with disabilities to participate equally in any service intended for the general public and calls on governments to remove barriers to participation. Although this aspect was not addressed in the health-related studies examined, conceptual understanding of inclusive practices and attempts to advance inclusive education and mainstreaming people with disabilities into formal employment, vocational training and microfinance services is evident in Sri Lanka. Examples include opportunities provided to children in special education units who are ready for integration to be sent to non-special classes [9], vocational training programs for disabled youth that can enhance employment opportunities, and provision of finance for self-employment [77]. In spite of successes in several areas [78–80], low rates of schooling and employment among disabled people, poor coordination among different sectors in mainstreaming disability and equity in provision remain challenging needs [81].

Investing in programmes and services for people with disabilities

None of the studies eligible for review evaluated the provision of support services or training needed by people with disability. However a place for providing psychosocial support for people with mental disability [45,70], visual disability [21], physical disability [31–33], victims of family violence [57] and women exposed to trauma [55] is discussed in many studies as a way forward. Likewise, the provision of assistive devices such as optical support and hearing aids for children [19,20,28] and affordable spectacles for elderly [27] have been recommended.

Sri Lanka has a rapidly ageing population, and unlike high income countries facing similar demographic changes (e.g. Japan and parts of Europe), the health system and resources in Sri Lanka are substantially more constrained [12]. There is a need for careful planning of strategies to address the health and social needs of the country's ageing population, a topic receiving

increasing attention [12]. The establishment of geriatric clinics in government hospitals, inclusion of care of the elderly in Primary Health Care programmes [30], wider inputs from psycho-geriatrics and social services [29] and provision of assistance for the family support system for elderly care [38] are some recommendations that emerged from the studies examined.

The Sri Lankan government, non-governmental organizations and private institutions work in partnership to provide disability services through the Community Based Rehabilitation (CBR) programmes. Special services such as speech therapy and physiotherapy are provided by volunteers in the homes of children with disabilities who cannot go to school, whilst the community supports the programme by providing hearing aids, wheelchairs, crutches and other items needed [80]. Published studies reveal recommendations emphasizing the need to shift towards enhanced community-based options; consumer participation of people with communication disabilities [71], burn victims [35,36,82] and lymphoedema [33]; and the need for a culturally sensitive tool for early community-based screening for autism [18]. An overarching review of existing programmes and services for people with disability will help determine priorities for improving coverage, effectiveness and efficiency of services, as envisaged in the *World Report*.

Adopting a national disability strategy and plan of action

Disability-specific legislations and policies in Sri Lanka are summarized in Table 2. The National plan of action on disability is outlined in the National Disability Policy (2003) [83]. At present a new draft policy and action plan is under review. Sri Lanka has a disability law (*1996 Right of persons with Disabilities Act No. 28*) and sectoral disability regulations that cover education, employment, rehabilitation, health information and technology, building code, transportation, poverty alleviation and social security/welfare.

Published studies also recommend specific national strategies for burn care [82], for care of persons and families living with schizophrenia [68] and for mental health care for adolescents [48,49] and the elderly [38]. Strategies for monitoring progress of implementation must be built in to any new programme to ensure proper enforcement.

While Sri Lanka has not enacted disability-specific anti-discrimination legislation, the Protection of the Rights of Persons with Disabilities Act (No. 28 of 1996) and the Disability Rights Bill attempts to make domestic laws relating to disability rights more effective and consistent with the United Nations Convention on the Rights of Persons with Disabilities. However, in the absence of specific mechanisms for implementation and enforcement, and organized monitoring and reporting of progress, the utility of legislative instruments is unlikely to be realised. It is evident that addressing the discrimination and social stigma that people with disabilities face requires the government of Sri Lanka to review current policies, services and programmes, identify gaps and revise enforcement mechanisms.

Involving people with disabilities

People living with disabilities, parent groups and a range of support organizations, were represented through all stages of the formulation of the National Disability Policy in Sri Lanka, the draft committee itself being represented by people with all major types of disability [83]. The National Council for the Persons with Disabilities comprises people with disability who actively participate in the decision-making process and who serve in sub committees such as the legal advisory board, finance, housing and mental health policy for persons with disabilities [9]. Their involvement in all decision-making processes related to

Table 2. Disability-specific legislation and policies in Sri Lanka.

Legislation or policy	Salient aspects
Disability Rights Bill (2006)	Includes rights for non-discrimination, participation in decision making, employment, vocational training and skills development, poverty alleviation, education, health, sports, transport, built environment, housing, social security, communication and information, assistive devices, family and community life, and rights of children, youth, women and elders with disabilities.
Disabled Persons' Accessibility Regulation No. 01 (2006)	All new constructions, renovations and modifications of public buildings and transport to conform to accessibility guidelines, and all existing public buildings to be made accessible within three years (now postponed until 2014).
National Disability Policy (2003)	Covers mainstream policy and programmes and specific services for persons with disability (New draft policy 2012/13).
Ranaviru Seva Act (1999)	Provides for the care and rehabilitation of members of the armed forces and police force who have become disabled in the line of duty and promotes the welfare of them and dependents of those killed or missing in action.
Special Educational Society (Incorporation) Act No. 3 (1999)	Covers the rehabilitation of disabled persons, by providing educational services and engaging them in social services, awarding grants, providing aid and assistance to victims of natural disasters, protecting the rights of disabled persons, and provision of nutritious food, medical facilities, vocational training and employment to disabled persons.
General Educational Reforms (1997)	The inclusion of children who have disabilities in ordinary classroom.
Protection of the Right of persons with Disabilities Act No. 28 (1996)	Promotes advancement and protection of rights of persons with disabilities in Sri Lanka including the establishment of the National Council and the National Secretariat for Persons with Disabilities.
Social Security Board Act 17 (1996)	Pension and insurance benefits for people with disabilities in the case of accidents or old age.
National Health Policy (1996)	The improvement of quality of life and early childhood development of children with disabilities in rehabilitation including pre-schools, house visits, assistive devices, parental counselling and awareness for children suffering from acute and chronic mental illnesses.
Workmen's Compensation Act No. 19 (1934), (Amended in 1957 and 2005)	Provides for the payment of workmen compensation to those injured in the course of their employment.
Public Administration Circular No. 27/88 (1988)	Three percent of vacancies in public services and public companies to be filled by people with disabilities.
Mental Diseases Act No. 27 (1956)	Provides for better care and custody of persons with mental disability.

the implementation of the policy is vital to ensure its fullest impact and continuing relevance to their changing needs. None of the reviewed studies examined the involvement of people with disability in formulating and implementing health policies, laws and services or in designing and conducting research on disability.

Improving human resource capacity

Interventions that modify negative attitudes among medical students towards people with mental illnesses [67] and training in the practical aspects of integration of mental health interventions with community-based rehabilitation (CBR) [76] are some recommendations made in studies reviewed. The need to train more neurologists and the need to establish neuro-rehabilitation as a sub-speciality of neurology training were strategies recommended in studies on stroke care [65,84]. The need to increase the number of eye-care practitioners is also highlighted [27].

Improvement in human resource capacity through effective education, training and recruitment is recommended in the *World Report*. Current demand for human resources for health in Sri Lanka is expressed through cadre requirements that are not necessarily based on the real demand or need [85]. Moreover, the present availability of over 290 health staff categories is based on policy decisions taken many years ago. The need for new categories for further strengthening of the community health services such as community nursing, counselling, occupational therapy, elderly and rehabilitation care and eye care at community level should be considered. Higher education institutes need to develop courses accordingly so that staff working in sectors such as rehabilitation, care giving, speech and language therapy and in special education are increased in Sri Lanka based on needs. To date only one Medical Faculty in Sri Lanka has a dedicated Department of Disability Studies in which all current and future training of the professions (e.g. speech therapy, audiology and occupational therapy) under its auspice are to have their curriculum underpinned by a disability studies paradigm.

Overall, a review of disability-related knowledge and competencies of health staff and the incorporation of relevant training on disability, including in-service training requires the attention of educators and administrators in Sri Lanka.

Providing adequate funding and improving affordability

The *World Report* recommends improving funding of public services for people with disability in a way that it reaches all targeted beneficiaries. The need for specialist health care units such as for burns [36,82] and strokes units [65,84] and making certain drugs and therapies accessible to all Alzheimer's patients in Sri Lanka [70] were recommendations in some of the studies examined. There is a critical need for robust cost-effectiveness analyses, particularly given scarce resources and competing public health priorities.

The government of Sri Lanka provides a monthly allowance to disabled people with low family income and provides financial assistance for surgeries, medicine and for self-employment [77]. People with disabilities from low income families who own land are provided funds for construction of a new house. Financial support is also provided to individuals to construct accessible facilities at home. The quantum of such support varies depending on the need of the individuals. Free bus passes are given to ex-combatants with disabilities and transport allowances paid to children attending special schools and those who attend vocational training institutions. Assistive devices such as wheel chairs, tricycles, crutches, white canes, hearing aids and spectacles are provided by the government, non-governmental organizations, the private sector and civil society groups and individuals, a common practice in a predominantly Buddhist culture.

Sri Lanka's social protection system is much more extensive than other South Asian countries. However, disability programs in Sri Lanka do not reach all those who are poor [81]. Compensation for disability is primarily focused on disabled soldiers injured in the conflict (up to 85% of total budget of the Ministry of Social

Welfare), leaving other disabled groups under-covered. Only 41% of the people with disability receive any sort of income transfer, including the disability allowance, from the government. To achieve health equity based on the social determinants of health, Sri Lanka should develop a more comprehensive approach to address inequities in disability.

Increasing public awareness and understanding about disability

Knowledge, beliefs and attitudes about disability among the general population is not reported in any of the studies examined, which if available would help identify gaps in public understanding. The need of implementing the National Disability Policy in Sri Lanka focusing on raising awareness and reducing stigma, has been highlighted previously [81]. Governmental and non-governmental agencies and disabled people's organizations must implement campaigns to increase public knowledge and understanding of disability.

Improving the availability and quality of data on disability

There is an acute need for national data on disability in Sri Lanka and methodologies for collecting such data need to be developed as a priority. Disaggregation of such data based on age, sex and socio-economic status will help uncover patterns and trends, remove disabling barriers and provide better quality services. Of the studies examined, only one study (on burns) highlighted the need for better quality data [82].

Strengthening and supporting research on disability

Health research on disability in Sri Lanka covers a range of topics, the major areas of focus being mental health, visual disability and disability-related health care delivery. However, many types of disability, particularly intellectual disability and many aspects of disability such as, impact of health policies, attitudes of health care providers, quality of life, barriers to education and training of people with disability in health care delivery, accessibility to health care have not been addressed. Some studies highlight the need for further research on dementia [42], depression [45,46,48], mental health disorders [58], elderly disablement [41] and alcohol dependence [75]. Universities in Sri Lanka should focus on building a critical mass of researchers on disability linking up with disabled people's organization and international universities providing opportunities for international learning.

Particular issues pertaining to Sri Lanka

Disability as a consequence of the long standing civil war and natural disasters such as the 2004 Boxing Day tsunami, are particular issues for Sri Lanka that require attention. Although the exact numbers are uncertain and likely to be underestimated, the civil war which lasted for almost 30 years has left many Sri Lankans, particularly those residents in the North East regions of the country, both physically and psychologically disabled. Studies reporting on victims of war [50,51], injured combatants [32] and landmine victims [31] highlight the need for interventions that can address significant levels of emotional trauma [31,32,50,51]. Somasundaram [51] notes the important role of psychosocial regeneration of the family and community structure that could help in personal and community healing. The need for proper management of post-traumatic stress disorder among victims of war and natural disasters is also highlighted [32,55].

The 2004 tsunami affected primarily those living in the South East regions of the country, resulting in over 32 000 deaths and leaving over half a million homeless. Training of teachers and primary care workers [86], and school-based interventions [87] have had promising results in alleviating distress and

post-traumatic symptoms in children and adolescents. The need for psychosocial and mental health interventions for senior victims [88] and the need to examine how disasters and relief interventions influence relationships and dynamics in society [89] have been highlighted.

While the cross-cutting recommendations made in the *World Report* are applicable in addressing the issues relevant to both the consequence of the civil war and the 2004 tsunami, the toll that these events have taken on large segments of the population calls for urgent action targeting the longer-term health and wellbeing of these vulnerable populations.

Conclusion

Overall, published studies on health-related research in Sri Lanka address several of the key recommendations of the *World Report* and collectively identify areas that require priority attention to promote the health and wellbeing of people living with disability in the country. A more focussed approach to disability-research will help identify needs, optimize resources and provide equal opportunities to people with disability to fulfil their potential.

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Declaration of interest

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