

An elucidation of Public Health Policy for People with Disability in India

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ABSTRACT

The problems of people with disability and their families have to face much more problems in developing countries as compared to disabled people in developed nations. In comparison to developed nations there is lack of proper education, health and medical facilities in developing nations. The problem of improving the condition of people with disability seems to be extremely complex in developing nations. It calls for serious attempt on improving the condition of disable people. This research paper attempted to focus on health area of the people with disability with special reference to India. Generally, there is lack of political will and administrative accountability, proper funding and technical assistance for them in India. Moreover, health policies are not accessible, affordable due to restricted financial flow to the policies and programs related to support people with disability. People with disabilities experience lower rates of employment, are more likely to be economically disadvantaged, and are therefore less likely to afford private health insurance and health care. An effort has been made in paper to discuss the health condition of people with disability in India. The central focus of the paper is to throw light on the health conditions of the people with disability while critically analysing legislative measures and health policies for them in India. It calls for serious attempt on improving their health conditions condition. Medical and health services should be free or affordable for people with disability. Priority should be given to people with disability in accessing credit on soft terms from banks and other financial institutions for getting medical facilities. They should get assistance by International and national governments in getting their health services. Policy formulated at the national level will be effective only when they are accompanied with strong political will and administrative accountability.

Keywords: People with Disability, Health related Problems in India, Public Health Policy, Disability.

INTRODUCTION

Health is “a state of physical, mental, and social well-being and not merely the absence of disease or infirmity”¹. Good health is a prerequisite for participation in a wide range of social activities including education and employment. Individual factors, living and working conditions, general socioeconomic, cultural and environmental conditions, and access to health care services are some of the factors which impact on health.² Article 25 of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) emphasizes the right of persons with disabilities to attain the highest standard of health care, without discrimination³.

Disability and Health: Many Studies indicate that people with disability experience more health problems than the people without disability. People with disability are more at:

1. **Risk of Premature Death:** People with schizophrenia and depression have an increased risk of premature death (2.6 and 1.7 times greater, respectively).⁴
2. **Risk towards Health Problems:** People with disabilities experience the same health problems that affect the general population, such as influenza and pneumonia. According to a study, people with disabilities experience more health problems than the general population⁵.
3. **Susceptible to Develop Chronic Conditions:** Some may be more susceptible to developing chronic conditions because of the influence of behavioral risk factors such as increased physical inactivity⁶.
4. **Earlier Onset of Risk Conditions:** They also may experience earlier onset of risk conditions.⁷
5. **More prone to onset of chronic health conditions:** One study indicated that adults with developmental disabilities had a similar or greater rate of chronic health conditions such as high blood pressure, cardiovascular disease, and diabetes than people without disabilities.⁸ The prevalence of diabetes in people with schizophrenia is around 15%, compared with the general population rate of 2–3%⁹.

¹Constitution of the World Health Organization. Geneva, World Health Organization, 1948 (<http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf>, accessed 9 June 2015).

² *Closing the gap in a generation: Health equity through action on the social determinants of health*. Geneva, World Health Organization, 2008.

³United Nations *Convention on the Rights of Persons with Disabilities*. Geneva, United Nations, 2006 (<http://www2.ohchr.org/english/law/disabilities-convention.htm>, accessed 19 June 2014).

⁴ Prince M et al. No health without mental health. *Lancet*, 2007,370:859-877. doi:10.1016/S0140-6736(07)61238-0 PMID:17804063

⁵ Rimmer J. H, Rowland JL. Health promotion for people with disabilities: implications for empowering the person and promoting disability-friendly environments. *Journal of Lifestyle Medicine*, 2008,2:409-420. doi:10.1177/1559827608317397

⁶ *Ib.id*

⁷ Doyle J, Wong LL. Mismatch between aspects of hearing impairment and hearing disability/handicap in adult/elderly Cantonese speakers: some hypotheses concerning cultural and linguistic influences. *Journal of the American Academy of Audiology*, 1996,7:442-446. PMID:8972445

⁸ Mathers C, Smith A, Concha M. *Global burden of hearing loss in the year 2000*. Global Burden of Disease, 2000 (http://www.who.int/healthinfo/statistics/bod_hearingloss.pdf).

⁹ Schneider M et al. Measuring disability in censuses: the case of South Africa. *European Journal of Disability Research*, 2009,3:245-265.

6. **Sexual and Reproductive health Risks:** Adolescents and adults with disabilities are more likely to be excluded from sex education programmes like programs on HIV etc¹⁰. A national study in the United States showed that women with functional limitations were less likely to be asked about contraceptive use during visits to general practitioners.¹¹

According to the *World Health Survey* data there is a significant difference between men and women with disabilities and people without disabilities in terms of the attitudinal, physical, and system level barriers faced in accessing care.¹²

Some of the main problems faced by persons with disabilities are physical inaccessibility and financial barriers in accessing health care.¹³ In addition to these barriers, there is the general problem of qualitatively poor health care services. Despite the Government of India and the State Governments having introduced several health schemes for the needs of the disabled, these do not adequately ensure their right to full and equal healthcare. The right to health as covered under the UN Convention on the Rights of Persons with Disabilities (“UNCRPD”) requires that the State shall ensure that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability and that States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation and the State shall take all measures to ensure that such a right is made a reality.¹⁴

According to Convention of disability, states shall take effective measures for people with disability:

- **Quality and standard of free or affordable health care and programmes**
- **Measures for early identification and intervention for disability:** Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities.
- **Preventive Measures:** to minimize and prevent further disabilities, including among children and older persons;

¹⁰ *The forgotten: HIV and disability in Tanzania*. Dar es Salaam, Tanzanian Commission for AIDS, 2009 (<http://www.gtz.de/de/dokumente/gtz2009-en-hiv-and-disability-tanzania.pdf>, accessed 5 April 2010).

¹¹ Chevarley FM et al. Health, preventive health care, and health care access among women with disabilities in the 1994–1995 National Health Interview Survey, Supplement on Disability. *Women’s Health Issues: official publication of the Jacobs Institute of Women’s Health*, 2006,16:297-312. doi:10.1016/j.whi.2006.10.002 PMID:17188213

¹² *World Health Survey*. Geneva, World Health Organization, 2002–2004 (<http://www.who.int/healthinfo/survey/en/>, accessed 10 September 2010).

¹³ United Nations Development Programme, Official Records, U.N. Document Available at <http://www.un.org/disabilities/default.asp?id=18>, Accessed 10 March 2015.

¹⁴ Convention on the Rights of Persons with Disabilities, United Nations, Available at <http://www.un.org/disabilities/convention/conventionfull.shtml> Accessed 2 February 2016

- **Equal access to Health Services:** in urban as well as rural areas
- **Awareness Generation of Human Rights:** So that they can live a dignity full, autonomous life.
- **Equality and Prohibition of Discrimination against people with disability:** Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability

Out of the total population of Persons with Disabilities, about 1.50 crore are male and 1.18 crore female. These include persons with visual, hearing, speech and loco-motor disabilities; mental illness, mental retardation, multiple disabilities and other disabilities

According to Census of India, people having disabilities (in laks):

- **In Seeing** 50.32 (18.8%)
- **In Hearing** 50.71 (18.9%)
- **In Speech** 19.98 (7.5%)
- **In Movement** 54.36 (20.3%)
- **Mental Retardation** 15.05 (5.6%)
- **Mental Illness** 7.22 (2.7%)
- **Any Other** 49.27 (18.4%)
- **Multiple Disability** 21.16 (7.9%).¹⁵

Other legislative measures for Persons with Disabilities: -

1. **The Rehabilitation Council of India Act, 1992¹⁶:** The Rehabilitation Council of India was set up under the Act. The Council regulates and monitors the training of rehabilitation professional and personnel and promotes research in rehabilitation and special education. The Council has been entrusted with the following functions: -

1. **It recommends training policies and programmes in the field of rehabilitation:** To regulation of the training policies and programmes in the field of rehabilitation of persons with disabilities. Besides providing training council standardization of training courses for professionals dealing with persons with disabilities.
2. **Recognition of institutions providing education in the field of rehabilitation of persons with disabilities:** Beside promoting of degree programs in educational institution, it encourage research in the field of Rehabilitation and Special Education.
3. **Recognition of Vocational Rehabilitation Centres**
4. **Register personnel working in national institutes and apex institutions**

¹⁵ Census of India 2011.

¹⁶ Available at <http://www.rehabcouncil.nic.in/forms/Sublink1.aspx?lid=798> Accessed 3 march 2015.

2. **Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (the Act)** was enacted to give effect to the Proclamation on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region adopted in the meeting convened by the Economic and Social Commission for Asia and Pacific held from 1st to 5th December, 1992. The Act directed certain obligations on the Central Government, State Governments and the local authorities to take special measures for persons with disabilities in India for their;

- prevention and early detection of disabilities;
- education;
- employment;
- provision of aids and appliances;
- access to public places;
- transport, etc.

3. **The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.**¹⁷

Provisions under this act are as follows:

- Constitution of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities;
- Setting up of Local Level Committees;
- Appointment of Guardians.

THE NATIONAL POLICY FOR PERSONS WITH DISABILITIES, 2006 With a view of providing better quality of life, equal opportunities and effective access to rehabilitation measures, the Government, with a view to create an environment that provides such persons equal opportunities for protection of their rights and full participation in society, formulated and brought out the National Policy for Persons with Disabilities.

Some of the Policy formulated for the people with disability are as follows:

- I. Prevention of Disabilities
- II. Rehabilitation Measures
 - A. Physical Rehabilitation Strategies: Early Detection and Intervention w Counselling and Medical Rehabilitation, providing ssistive devices and development of rehabilitation professionals
 - B. Education for Persons with Disabilities

¹⁷ Available at: <http://socialjustice.nic.in/pdf/ntact1999.pdf> Accessed 3 February 2015.

- C. Economic Rehabilitation of Persons with Disabilities: Measures for their employment in Government Establishments, wage employment in private sector, Self-employment
- III. Provisions for Women with Disabilities
- IV. Provisions for Children with Disabilities
- V. Barrier-free Environment
- VI. Issue of Disability Certificates
- VII. Social Security
- VIII. Promotion of Non-governmental Organizations (NGOs)
- IX. Collection of regular information on Persons with Disabilities
- X. Research
- XI. Sports, Recreation and Cultural life
- XII. Amendments to existing Acts dealing with the Persons with Disabilities.

The following mechanism is in place for implementation of the National Policy:

Coordination of various Departments: Department of Disability Affairs, Ministry of Social Justice & Empowerment is the nodal Department to coordinate all matters relating to implementation of the Policy.

The Central Coordination Committee, with stakeholder representation, coordinates matters relating to implementation of the National Policy. There is a similar Committee at the State level.

Local Rehabilitation Centres: Panchayati Raj Institutions and Urban Local Bodies are associated in the functioning of the District Disability Rehabilitation Centres. They are required to play a crucial role in the implementation of the National Policy to address local level issues. **The Chief Commissioner for Persons with Disabilities at Central level and State Commissioners at the State level,**

Other Steps initiated for people with Disability in India

- i. **Country Report.**
- ii. **The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities**

Major activities conducted during the year 2013-14¹⁸ under various Schemes and Programmes of The National Trust are:

- a) Niramaya (Health Insurance) Scheme.
- b) Sahyogi – Care Givers’ Training Scheme Under the Scheme
- c) Care Givers Cells (CGCs) have been set up in selected NGOs across the country. Care Givers’ Training is provided under the Scheme by experts and professionals.

¹⁸ Annual Report 2013-14, Ministry of Social justice and empowerment, Department of Empowerment of People with Disability.

- d) Association for Rehabilitation under National Trust Initiative of Marketing (ARUNIM)
- e) State Level Coordination Committee (SLCC)
- f) Niramaya (Health Insurance) Scheme
- g) Sahyogi – Care Givers’ Training Scheme Under the Scheme
- h) Association for Rehabilitation under National Trust Initiative of Marketing (ARUNIM).
- i) SAMARTH 2014 to provide opportunities artisans with disabilities
- j) 6Up-scaling Early Intervention Activities Early Intervention for children with Developmental Delays and Disability requires both medical and non-medical interventions.
- k) Sambhav : A National Resource Centre Sambhav - a National Resource Centre for Persons with Disabilities has been established in Delhi by Action for Ability Development and Inclusion
- l) Up-scaling Early Intervention Activities Early Intervention for children with Developmental Delays and Disability requires both medical and non-medical interventions.
- m) Badhte Kadam : A pan - India Awareness Raising Programme Badhte Kadam is a pan-India Awareness Raising Campaign, which is organized every year, all over India, by The National Trust.
- n) Gharaunda : Life Long Shelter and Care Scheme Group Home and Rehabilitation Activities for Disabled Adults (GHARAUNDA) under The National Trust, was launched to provide ‘Life Long Shelter and Care Facilities’ through empanelled Service Providers, to adult persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.
- o) Uddyam Prabha : Incentive Scheme Uddyam Prabha is an incentive scheme to promote economic activities for self–employment of the persons with disabilities.
- p) Mentors’ Training Programme on Self-
- q) On-line Autism Information and Resource Centre Portal
- r) Lotika Sarkar Endowment Fund
- s) Satellite Channel : ‘NAVSHIKHAR’
- t) Seminars/Workshops/Refresher programmes

Solutions

1. **Health Policy Reform and legislations:** International, regional, and national policy and legislation can help meet the health care needs of people with disabilities.
2. **International aid and Assistance:** There are several international conventions such as CRPD, MDGs which not only provide guidelines for several social welfare programs but also aid financially and mechanically to several nations. There are several programs started under international agencies

like UNESCO that provide countries with rationale and support to improve availability of health care for people with disabilities.

Accommodations	Suggested Approaches
Structural modifications to facilities	Ensuring an accessible path of travel from the street or transit to the clinic; allocating adequate parking bays for people with disabilities; configuring the layout of examination rooms and other clinic spaces to provide access for mobility equipment or support people; installing ramps and grab rails; widening doorways; clearing hallways of equipment obstructing the path of travel; installing lifts; high contrast, large print and Braille signage; providing modified toilets and hand washing facilities; providing seating for those who cannot stand or sit on the floor to wait.
Using equipment with universal design features	Height-adjustable examination tables or availability of a lower cot or bed for examination; seated or platform scales; wheelchair accessible diagnostic equipment: for example, mammography equipment.
Communicating information in appropriate formats	Presenting health information in alternative formats such as large print, Braille, audio and picture format; speaking clearly and directly to the individual; providing information slowly to ensure comprehension; demonstrating activities rather than just describing them; sign language interpreting services; providing readers, scribes, or interpreters to assist with forms.
Making adjustments to appointment	Provisions for making appointments via e-mail

systems	or fax; sending text or phone appointments reminders; scheduling additional time for appointments; offering first or last appointments; clustering appointments for general health and disability needs.
Using alternative models of service delivery	Telemedicine; mobile clinic services, and house calls; involving family members and caregivers in medical consultations when appropriate and desired by the patient; assistance
<i>Source: World Report on Disability (2011). World Health Organisation (WHO)/ World Bank, Geneva: p. 74</i>	

3. **Political will and administrative accountability:** Policy formulated at the international level will be effective only when they are accompanied with strong political will and administrative accountability.¹⁹
4. **Proper Funding and Technical Assistance:** Health policies can be accessible, affordable, available only when there is unrestricted financial flow to the policies and programs related to support people with disability. Medical and health services should be free or affordable for people with disability. People with also disabilities experience lower rates of employment, are more likely to be economically disadvantaged, and are therefore less likely to afford private health insurance and health care; they must be assisted by International and national governments in getting health services etc.²⁰
5. **Technical assistance:** technical knowhow and assistance is also essential to for policies and programmes for proper treatment and care of people with disability. Staff, and health workers should be properly trained to assist people with disability.

¹⁹ Kickbusch I. The development of international health policies—accountability intact? *Social Science & Medicine* (1982), 2000,51:979-989. doi:10.1016/S0277-9536(00)00076-9 PMID:10972440

²⁰ White PH. Access to health care: health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics*, 2002,110:1328-1335. PMID:12456953

6. **Physical Activities:** Evidence shows that health promotion interventions such as physical activities are beneficial for people with disabilities.²¹ But health promotion activities seldom target people with disabilities, and many experience multiple barriers to participation.
7. **Communication with people with Disability:** Communication is an area of concern with people with disability. For instance a deaf person may feel difficulty in communication with service providers. Difficulties can arise when people with disabilities attempt to make appointments with service providers, provide a medical history and description of their symptoms, or try to understand explanations about diagnosis and management of health conditions. Inaccurate case histories may be provided to health-care practitioners when information is supplied by caregivers, family members, or others.²²
8. **Recreational and Health Promotion Efforts:** Recreational programmes and other health promotion efforts like fitness program or weight loss programmes targeted at people with disability can have a substantial impact positively on improving lifestyle and behavior. It enhances the quality of their lives as well as reduces medical costs of people with disability.²³

Conclusion: Even rights such as the right to education and employment would be meaningless unless persons with disabilities have access to adequate healthcare as without adequate health care, no person would be able to avail of any employment or education opportunities.

²¹ Allen J et al. Strength training can be enjoyable and beneficial for adults with cerebral palsy. *Disability and Rehabilitation*, 2004,26:1121-1127. doi:10.1080/09638280410001712378 PMID:15371024

²²Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research: JIDR*, 2004,48:142-149. doi:10.1111/j.1365-2788.2004.00503.x PMID:14723656

²³ Drum CE et al. Guidelines and criteria for the implementation of community-based health promotion programs for individuals with disabilities. *American Journal of Health Promotion: AJHP*, 2009,b24:93-101, ii. doi:10.4278/ajhp.090303-CIT-94 PMID:19928482