



A Profile of Disability in Odisha

TRENDS, DEVELOPMENT & DYNAMICS



WCD Dept., Govt. of Odisha



A Profile of Disability in Odisha

— TRENDS, DEVELOPMENT & DYNAMICS —



WCD Dept., Govt. of Odisha



© Swabhiman - State Disability Information and Resource Centre

Edition

April, 2012

Document Design and Production by

Swabhiman

Research Team Leader

Dr. Sruti Mohapatra

Available at Swabhiman

₹. 1500/-

Designing and Printing By

Digital Graphics

2415, Jayadev Vihar, Bhubaneswar

+91 9938517657, digitalgraphics06@gmail.com

Contents

Foreword	i
Preface	iii
Acknowledgment	v
Abbreviations and Acronyms	vi
Voices	ix
Executive Summary	xii
1. Study Overview	1
1.1 Objective	5
1.2 Methodology	5
1.3 Sample size	5
2. Key Observations	9
(Each chapter is followed by recommendations)	
2.1 Public Perception and Societal Attitude	11
2.2 Access	21
2.3 Population	33
2.3.1 Category of respondents	38
2.4 Acquiring Disability	39
2.5 Knowledge of Laws	43
2.5.1 Level of awareness	45
2.5.2 Source of information	49
2.6 Government Entitlements	51
2.6.1 Disability certificate	53
2.6.2 Disability pension	57
2.6.3 Aids and appliances	59
2.7 Education	63
2.7.1 Primary education	66
2.7.2 Higher education	70
2.8 Livelihood, Employment and Poverty	83
2.8.1 Employment and Livelihood	87
2.8.2 Vocational Training	92
2.8.3 Poverty	94
2.9 Health, Water and Sanitation	99
2.9.1 Health	101
2.9.2 Water and Sanitation	104

2.10	Marriage and Parenthood	109
2.10.1	Marriage	111
2.10.2	Parenthood	114
2.11	Social Life and Leisure	119
2.11.1	Social life and exclusion	120
2.11.2	Leisure	123
2.12	Political Participation	127
2.13	Law, Justice and Grievance Redressal	135
2.13.1	Law	136
2.13.2	Justice	138
2.13.3	Grievance redressal mechanism	139
2.13.4	Discrimination	139
2.14	Networking	143

3. SWOT Analysis **147**

List of Annexures

Annexure 1	People first language	149
Annexure 2	Field research team	150

List of Graphs

Graph 1	CWSN to attend the regular schools	14
Graph 2	Willingness to employ PWD	15
Graph 3	Willingness to have PWD as colleagues	16
Graph 4	Perception of sexual relationships by PWD	17
Graph 5	Level of comfort with PWD as neighbors	18
Graph 6	Structural access	24
Graph 7	Ramps	25
Graph 8	Structural access to public and private institutions	28
Graph 9	Access to public utility facilities	29
Graph 10	Communication and mobility access in public and private institutions	30
Graph 11	Estimates of disability Census 2001	36
Graph 12	Estimates of disability NSSO 2002	36
Graph 13	Awareness of PWD Act among PWD	47
Graph 14	Awareness of laws for disabled among PWD	47
Graph 15	Response of teachers and parents to inclusive education	56
Graph 16	Comparative figures of the aware and the recipients of aids and appliances	60
Graph 17	Response of teachers and parents to inclusive education	70
Graph 18	Joy of learning	76
Graph 19	Educational aid support received from college	78

Graph 20	Scholarship recipients	79
Graph 21	Scholarship amount	79
Graph 22	Scholarship disbursement	80
Graph 23	Average monthly income	87
Graph 24	Number of PWDs who earn a living	88
Graph 25	Profit in small business	91
Graph 26	Access to health facilities	101
Graph 27	PWD who voted in 2009 Assembly elections	130
Graph 28	Empathy of elected representative	132
Graph 29	Empathy of parties	133

List of Tables

Table 1	Sample size derivation	7
Table 2	Number of respondents	8
Table 3	Awareness of disability	13
Table 4	Society creates barriers for PWD	13
Table 5	Are PWDs treated fairly in society?	13
Table 6	PWD should receive equal opportunities in terms of education	14
Table 7	PWD should receive equal opportunities in terms of employment	15
Table 8	Willingness to have PWD as colleagues	16
Table 9	Do PWD have a right to sexual relationships?	17
Table 10	Level of comfort in PWD as neighbors	18
Table 11	Features of ramp	25
Table 12	Accessible elevators	25
Table 13	Floor surface and tonal contrasts	26
Table 14	Accessible toilets	26
Table 15	Access in banks	27
Table 16	Access in post offices	27
Table 17	Access in restaurants/hotels	27
Table 18	Structural access	28
Table 19	Utility access	29
Table 20	Communication access	30
Table 21	Prevalence of disability in the member countries of WHO (S.E Asia)	34
Table 22	District-wise population of persons with disability in Odisha as per 2001 Census data	35
Table 23	Rural/Urban and sex wise prevalence of various types of disabled persons in Odisha as per 58th Round of NSSO data	37
Table 24	Prevalence of disability in various states of India	38
Table 25	Causes of disabilities	41

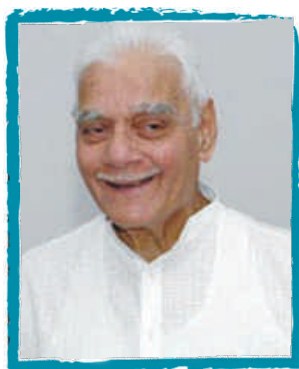
Table 26	Disabilities at and just after birth	41
Table 27	Awareness of PWD Act among persons with disability in Odisha	46
Table 28	Sources of information of PWD Act	49
Table 29	Possession of disability certificates (district wise)	55
Table 30	Reasons for non-possession of disability certificates	57
Table 31	Recipients of disability pension	58
Table 32	Awareness of free distribution of aids and appliances	59
Table 33	Recipients of aids and appliances	59
Table 34	Common aids and appliances distributed	60
Table 35	Literacy rate	66
Table 36	Identification and enrollment of CWSN in SSA schools	67
Table 37	Details of infrastructure modification and provision of aids and appliances	68
Table 38	Corrective surgeries on CWSN	68
Table 39	Response of school going CWSN	68
Table 40	Response of school teachers	69
Table 41	Number of students with disabilities in University	71
Table 42	Participation of students with disabilities in sports	72
Table 43	HEPSN and TEPSE status	73
Table 44	Educational support requirement	78
Table 45	Number of PWD who earn a living	87
Table 46	Average monthly income of PWD	87
Table 47	Livelihood sectors	88
Table 48	Number of PWD in job	89
Table 49	Job categories	89
Table 50	Small business by PWD	90
Table 51	Source of seed capital for small business	90
Table 52	Profit in small business	90
Table 53	Number of days of wage earning	91
Table 54	Awareness of VRC Bhubaneswar	92
Table 55	Awareness of VTC run by NGO	93
Table 56	Quality of training in VRC Bhubaneswar	93
Table 57	Quality of training in VTC run by NGOs	93
Table 58	Is vocational training leading to job placements?	94
Table 59	Enough income to take care of family needs	95
Table 60	Savings	95
Table 61	Utilization of savings	96
Table 62	Housing	96
Table 63	Access to health facilities	101

Table 64	Type of health facility PWD use	102
Table 65	Type of health facility Urban PWD use	103
Table 66	Type of health facility Rural PWD use	103
Table 67	Common health ailments	104
Table 68	Access to clean water	106
Table 69	Source of water supply	106
Table 70	Kind of latrine	107
Table 71	Marriage and child bearing	111
Table 72	Life partner	113
Table 73	Marital status	113
Table 74	Willingness for marriage	114
Table 75	Desire for parenthood	116
Table 76	Domestic chores assigned	121
Table 77	Access to family dining	122
Table 78	Access to family dining disability wise	122
Table 79	Experience with neighbors	123
Table 80	Experience with relatives	124
Table 81	TV watching	125
Table 82	Visit to fairs and festivals	125
Table 83	Shopping	125
Table 84	Participation in sports	125
Table 85	Participation in cultural activities	126
Table 86	Special arrangements for PWD in polling stations	131
Table 87	Awareness of PWD about ruling party in Odisha	132
Table 88	Knowledge of Chief Minister	133
Table 89	Knowledge of Prime Minister	133
Table 90	History of formation of state disability commission	145

List of Boxes

Box 1	Chapter VIII- Non-discrimination (PWD Act 1995)	22
Box 2	Structural access in Odisha	28
Box 3	Utility access in Odisha	29
Box 4	Communication access in Odisha	30
Box 5	International symbols of disability	31
Box 6	Chapter IV- Prevention and early detection of disabilities (PWD Act 1995)	45
Box 7	Awareness initiative 'Badhte Kadam'	48
Box 8	Awareness initiative 'Get Yourself Counted'	48
Box 9	World Bank Report (2004)	53

Box 10	Lacunae in the present methods of disability evaluation	54
Box 11	Observation report of medical boards and Bhima Bhoi scheme	56
Box 12	Progressive district Ganjam	61
Box 13	Chapter V - Education (PWD Act 1995)	64
Box 14	FGD at Utkal University, Bhubaneswar (VI Students)	77
Box 15	FGD at Chhatrapur, Ganjam (OH students)	77
Box 16	Chapter VI – Employment (PWD Act 1995)	85
Box 17	Chapter IV – Prevention and early detection of disabilities (PWD Act 1995)	100
Box 18	Excerpt from 'Access to Water and Sanitation for the disabled or the differently Abled'	105
Box 19	Marriage and child bearing	111
Box 20	Voices on marriage and parenthood	116
Box 21	Chapter I – Preliminary (PWD Act 1995)	121
Box 22	First political convention	129
Box 23	PWDs and elections	129
Box 24	PWD could not vote in 2009 elections	131
Box 25	Chapter XII - The chief commissioner and commissioners for PWD	137
Box 26	Strength of networking	144
References		151



Foreword

Around the world, an estimated one person in four is affected by disability, either directly, or as care-givers or family members. Far from being a minority issue, disability is something that can affect any of us at some point in our lives. The rights of those with disabilities are truly universal human rights. Raising awareness and promoting these rights is essential for the development of Odisha. It is now more than 16 years since the PWD (Persons with Disabilities) Act, 1995 was passed by the Parliament of India. Yet, we have not reached the entire population of disabled persons in Odisha. In the years ahead, disability will be an even greater concern because its prevalence is on the rise. This is due to ageing populations and the higher risk of disability in older persons as well as the global increase in chronic health conditions such as diabetes, cardiovascular disease, cancer and mental health disorders. As across the world, so also in Odisha, persons with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than persons without disabilities. This is partly because they experience barriers in accessing services that many of us have long taken for granted, including health, education, employment, and transport as well as information. These difficulties are exacerbated in less advantaged communities.

Our vision for Odisha is one where no-one is left behind, where ordinary persons have a greater stake in the community in the form of higher wages, higher aspirations and more stable and secure lives, and where everyone has the opportunity to fulfill their potential. We need to ensure that persons with disability are a full part of this agenda. To achieve this we must empower persons living with disabilities and remove the barriers which prevent them participating in their communities; getting a quality education, finding decent work, and having their voices heard.

I welcome this report 'A Profile of Disability in Odisha – Trends, Development and Dynamics' brought out by Swabhimani and congratulate the Women & Child Development Department, GoO for having supported this endeavor. This report provides the evidence for initiating innovative policies and programmes that can improve the lives of persons with disabilities, and facilitate implementation of the United Nations Convention on the Rights of Persons with Disabilities, which came into force in May 2008 and was ratified by India 2009. This landmark international treaty reinforced our understanding of disability as a human rights and development priority.

This report makes a major contribution to our understanding of disability and its impact on individuals and society. It highlights the different barriers that persons with disabilities face – attitudinal, physical, and financial. Addressing these barriers is within our reach. This report suggests steps for all stakeholders – including governments, civil society organizations and disabled persons's organizations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce new and existing standards and legislation, to the benefit of persons with disabilities and the wider community. Persons with disabilities should be central to these endeavors.

We have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of persons with disabilities. We can no longer overlook the lakhs of persons with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine. The report makes recommendations for action and will thus be an invaluable tool for policy-makers, researchers, practitioners, advocates and volunteers involved in disability. It is my hope that, beginning with the PWD Act 1995, then the Convention on the Rights of Persons with Disabilities, and now with the publication of 'A Profile of Disability in Odisha – Trends, Development and Dynamics', this year will mark a turning point for inclusion of persons with disabilities in our society and all development programs.

I congratulate Dr. Sruti Mohapatra and her team for the high level of standards they have set up in the field of disability in Odisha. They have set up high expectations and allowed us all the opportunity to exceed those expectations. Sruti, I know how strongly you feel about the issue, and how long you have worked in making disability visible in Odisha. By freely giving your time, leadership and compassion you have given countless persons with disabilities, from across the state, support they need to move forward with confidence in life. You are a good example of how commitment and hard work pay off.

In her 2012 budget speech, respected madam President Smt. Pratibha Devi Singh Patil ji, president of India, announced the government's plan of creating a separate department of disability affairs. Government, at the center, is also considering new legislation for the disabled to replace the existing act.

In accordance with this, and the resolve of the Government of Odisha to fulfill its promise to uplift the socio-economic status of the people of Odisha, we are determined to pursue a deliberate program of salvaging our people from the precipice occasioned by poverty, backwardness, deprivation, disability and, indeed, obvious hopelessness. Working together, governments, the civil society, the corporate sector and disabled persons themselves will succeed in tackling the greatest challenges to make the dream 'Development with Inclusion' come true. This is my dream and vision for Odisha.

Sri Murlidhar Chandrakant Bhandare
His Excellency
Governor of Odisha
4th April, 2012
(Excerpts from speech)





Preface

In January 2000 I was invited by DPI regional office to be a part of the delegation to the twenty-third special session of the General Assembly on "Women 2000: gender equality, development and peace for the twenty-first century" at the United Nations Headquarters in New York from 5 June to 9 June 2000. I addressed in many small groups meetings about the concerns of women with disabilities and it is during that time that I had a face to face with the meaning of inclusion. Subsequently I have made several presentations on the concept of 'an inclusive world'. I argue that exclusion caused by comprehensive relative deprivation fosters inequality 'in both social and economic front' and therefore it is necessary to create inclusive structures to become leaders whether at the level of a city, a state or the world.

Around 10 per cent of the world's population, or 650 million people, live with a disability. They are the world's largest minority, excluded and living in isolation. This figure is increasing through population growth, medical advances and the ageing process, says the World Health Organization (WHO). In countries with life expectancies over 70 years, individuals spend on average about 8 years, or 11.5% of their life span, living with disabilities. The situation in Odisha and India is more acute.

Recent UN estimates suggest 85-90% of the global population of persons with disabilities residing in so-called developing countries. Census 2001 reported that 2.13% of the total population constitute persons with disabilities. In Odisha close to 2% the total population are persons with disability.

In Census 2011 an increase to 7-8% is expected. Despite the magnitude of the issue, both awareness of and scientific information on disability issues are lacking. There is no agreement on definitions and little nationally comparable information on the incidence, distribution and trends of disability. There are few documents providing a compilation and analysis of the policies and responses to address the needs of persons with disabilities in India.

In this grim scenario the quality of life of PWD (Persons with Disabilities) in Odisha can be easily understood. Most persons do not have basic access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities. Following the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD 2009), disability is increasingly being understood as a human rights issue. Development agencies and practitioners are increasingly recognizing disability as a key issue, inexorably linked to poverty, in the extension of human rights and citizenship. In 2002, James Wolfensohn, former President of the World Bank, stated that unless disability issues were addressed, the UN Millennium Development Goal targets would not be met.

Inaccessibility and prejudices in society make life difficult and prevent access to basic rights and services such as participating in political process, gaining access to justice, and engaging in meaningful economic and social activity. Addressing this is critical for achieving inclusive growth, the MDGs, and, most importantly, human dignity, human rights and social justice. Accessibility and inclusion involves breaking down the barriers that prevent their full participation in society. This includes, for instance, promoting positive attitudes and perceptions (e.g. disabled people in politics), modifying the built environment (e.g. ramps in public buildings), providing information in accessible formats (e.g. our website in large print) and making sure that laws and policies support the exercise of full participation and non-discrimination (e.g. employment discrimination laws). Acceptance of differences and celebration of diversity is a natural consequence of inclusion which governs leadership in today's global marketplace. The collaboration of different perspectives is an organizational asset and brings forth innovation and profit.

How do we mainstream disability issues, challenges, and solutions into vision, strategic planning, annual work plans, and, most importantly, budgeting? The report 'A Profile of Disability in Odisha – Trends, Development and Dynamics' is a response to this situation. It has come up with a lot of information on the socio-economic profile of people with disabilities in the state, the societal attitudes faced by them, and covers all major aspects of the lives of disabled persons vis-à-vis gaps in mainstreaming. It first provides an overview of the sampling method and category of respondents. It then presents the public perception of PWD and societal attitudes faced by them; this is followed by availability of access. The next chapter on education focuses on both primary and higher education, followed by chapter on employment, livelihood and poverty. The succeeding chapters deal with health, marriage, social life and political participation. Networking is the last chapter preceded by grievance redressal. The report suggests steps for all stakeholders – including governments, corporate houses, civil society organizations and disabled people's organizations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce new and existing standards and legislation, to the benefit of persons with disabilities and the wider community. PWD should be central to these endeavors.

We will feel humbled and honored if the document in any way will be an asset for government, NGOs, research workers, development organizations, corporate houses, banks, research institutions, educational bodies and any person or body requiring information on disability scenario to forge a pathway for long term planning, inter-organizational / departmental partnership and evolution of new schemes for the empowerment of persons with disabilities. It will enable us to explore primarily where and how it makes most sense for public sector interventions to improve the quality of life of PWD.

My vision is of an inclusive world. I believe we are capable of dreaming of a utopia and making it a reality. We can and must create an inclusive world, a world where the human spirit of co-existence triumphs over discord and a world in which we are all able to live a life of well being and dignity. I invite you to use the evidence in this report to help this vision become a reality. Together, we can make a difference.

Dr. Sruti Mohapatra
Chief Executive
Swabhiman
4th April 2012



Acknowledgement

I thank the divine for blessing me and my team with the opportunity of carrying out this research work 'A Profile of Disability in Odisha – Trends, Development and Dynamics'. I am deeply Indebted to my mother, Dr. Annapurna Devi, who has been very accommodative to cope up with all defaulting in my duties to her in my rush for the completion of this work.

Every research work evolves into an inevitable finding only through the diligent efforts of the people who have dedicated themselves and toiled hard. This acknowledgement is a small tribute to their meticulous and magnanimous help rendered in every walk of this work.

I am thankful to the field team led by Asit Kumar Behera for travelling to each and every district of Odisha, even when the mercury soared to 49°C and many a times walking for 10kms and more to reach a PWD in a remote village. I thank Rajesh Ranjan Mohanty, Bharati Mohapatra, Bikram Kishore Rana, Lokapriya Priyadarshini Kanungo, Manas Kumar Pradhan, Deepak Kumar Maharana, Brajendra Prusty, Debasis Das, Akshya Behera, Chintu Nayak, Joyti Prasan Patnaik, Sonali Das, Soumya Mishra, Susil Das, Manmohan Das, Kurban Khan, Pravat Ghadei and Girija Nandini Swain, for their dedication.

My heartfelt thanks go to all our respondents and participants of various focus group discussions for having enriched us with the information and recommendations. My special thanks to the following individuals and organizations- K. C. Pandab of Shradha Rourkela, Firoz Behera of Rourkela, Manjaraj Maharana of CAPARDS Jharasuguda, Umesh Purohit of Bolangir, DAPTA Kalahandi, YCDA Boudh, Sannyasi Behera, K.Anand Rao, Pragati of Rayagada, Prafulla Rout of NAB, Pradeep Agrawal of Nuapada, Prava of Balasore, teachers of different schools from across Odisha, Rita Jena of CATCH, Ajay Jena of PARIVAAR, Dolamani Pradhan of, Kalahandi and Kalyani Khatua of Jagatsinghpur. I thank Deputy Director Census, Prasad Tripathy, for census data and OPEPA for SSA data. I thank Mr. P.R.Das (Ex. Head ALIMCO) and Mr. R.K.Sharma (VRC) for their insights.

I thank Kishor Mohanty of Digital Graphics for the final lap of the journey - production of the work in print.

I thank Seema for taking such good care of me and enduring me in all my difficult moods. Without her I could not have done anything. I thank my team – Asit, Rajesh, Manas and Ranu for their encouragement and persistence which helped me to see the completion of this work.

I would like to extend my heartfelt gratitude to W & CD Department, Government of Odisha, for having believed in our concept and provided us financial support. I thank my brother, Priyadarshi Mohapatra, for having supported the printing of this book. I profusely thank my sisters Swati Panda, Gayatri Devi and Maitree Mohapatra; and my brother Debasis Patnaik for having supported the 'report release' function.

Abbreviations and Acronyms

AAC	Alternative Augmentative Communication
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
AIM	Accessible Instructional Materials
ALIMCO	Artificial limbs Manufacturing Corporation of India
APRLP	Andhra Pradesh Rural Livelihoods Project
ARUNIM	Association for Rehabilitation under National Trust Initiative of Marketing
ASD	Autism Spectrum Disorders
ASHA	Accredited Social Health Activist
AT	Assistive Technology
AWW	Aanganwadi Workers
BMVSS	Bhagwan Mahaveer Viklang Sahayata Samiti
CAPART	Council for the Advancement of People's Action in Rural Technology
CBA	Curriculum Based Assessment
CBC	Closed Captioning
CBR	Community Based Rehabilitation
CD	Community Development
CHC	Community Health Center
CP	Cerebral Palsy
CPWD	Commissioner for Persons with Disabilities
CWSN	Children with Special Needs
DB	Deaf-Blind
DD	Developmental Disabilities
DFID	Department of Foreign and International Development
DISTAT	UN Disability Statistic Compendia
DP	Disability Pension

DPO	Disabled Peoples Organization
DS	Downs Syndrome
ECE	Early Childhood Education
EIP	Early Intervention Program
ESCAP	Economic and Social Commission for Asia and the Pacific
GOI	Government of India
GoO	Government of Odisha
HI	Hearing Impaired
IAY	Indira Awaas Yojna
ID	Intellectual Disabilities
IDEA	Individuals with Disabilities Education Act
IEE	Individualized Educational Evaluation
IEP	Individualized Education Program
IGNDPS	Indira Gandhi National Disability Pension Scheme
IGNWPS	Indira Gandhi National Widow Pension Scheme
JSY	Janani Suraksha Yojna
LD	Learning Disability
MD	Multiple Disabilities
MMR	Mildly Mentally Retarded
Mod MR	Moderately Mentally Retarded
MOU	Memorandum of Understanding
MR	Mental Retardation
NCPED	National Centre for Promotion of Employment for Disabled People
NGO	Non-Government Organization
NHFDC	National Handicapped Finance and Development Corporation
NIHH	National Institute for the Hearing Handicapped
NIVH	National Institute for the Visually Handicapped
NSSO	National Sample Survey Office
NT	National Trust
OH	Orthopedically Handicapped
OPEPA	Orissa Primary Education Programme Authority

OT	Occupational Therapy
PCA	Personal Care Attendant
PD	Physical Disability
PHC	Primary Health Center
PT	Physical Therapy
PWD	Persons with Disability
RCI	Rehabilitation Council of India
SGRY	Sampoorna Grameen Rozgar Yojana
SGSY	Swaranjayanti Gram Swarozgar Yojana
SHG	Self Help Groups
SL	Sustainable Livelihoods
SSA	Sarva Siksha Abhiyan
SVNIRTAR	Swami Vivekananda National Institute of Rehabilitation Training and Research
SWD	Social Welfare Department
SWD	Students with Disability
TB	Tuberculosis
TCMH	Training Center for Teachers of the Mentally Handicapped
TCTD	Training Center for Teachers of the Deaf
TCTVH	Training centre for Teachers of the Visually Handicapped
TDD	Telecommunication Devices for the Deaf
TTY	Teletypewriter (phone system for the deaf)
UGC	University Grants Commission
UNESCO	United Nations Educational, Scientific and Cultural Organization
USAID	United States Agency for International Development
VI	Visual Impairment
VRC	Vocational Rehabilitation Centre
VTC	Vocational Training Centre
WCD	Women & Child Development Department
WHO	World Health Organization
WWD	Women with Disability
UNO	United Nations Organization
UNCRPD	UN Convention on the Rights of Persons with Disabilities
YWD	Youth with Disability

Disability certificate is like a passport for PWD, which enables them to avail the benefits, concessions etc. provided by government. There is a shortage of medical experts, particularly psychiatrists, audiologists, psychologists etc. to certify PWD.

R.K.Sharma, Rehabilitation Officer, VRC, Bhubaneswar

Our children are not getting disability certificates. Doctors write 'MR' (mentally retarded) even in case of CP or autism. Certification of 4 categories of PWDs mentioned in National Trust Act- 1995 (Autism, CP, MR & MD) needs to be strengthened.

Ajay Jena, President, OSCCPA

Improper identification for aids and appliances and unavailability of the required aids is a major problem. Old and outdated equipment should be removed from government's list and new aids and appliances should be purchased and distributed.

K.Anand Rao, Disability Activist, Ganjam

Government should appoint young individuals as district disability welfare officers or DSWOs rather the old persons. Young people are open to new ideas and more considerate.

P.R.Das, Ex Head of ALIMCO, Bhubaneswar

There are many hurdles in getting pension. The procedure of selection is wrong. The biggest difficulty are the government officers. They are not cooperative and treat us like beggars.

Tukuna Das, OH, Balugaon, Ganjam

Disability pension is too low to secure a meal three times a day. I am eating only once a day and, as a result, I am ill always

Digambar Digal, OH, Dunguriput, Koraput

Designers, architects, builders and engineers should keep in mind that disabled people also live in the city and that they have needs such as wheelchair ramps, designated parking spaces and special access. We are all part of society. And we too are taxpayers.

Madhabananda Ray, OH, Secretary AOOWH, Bhubaneswar.

Access for me is signages and sign language interpreters. When I filed a case of discrimination against NALCO in Odisha High Court, on my court date I was shocked to discover that there were no sign language interpreters to help me present my case.

Sushanta Dakua, HI, Puri

Sign language interpreters and text books in braille are immediate requirements for students to learn and gain knowledge, not just some certificates.

Sannyasi Behera, VI, Disability Activist, Bhubaneswar

Buildings ignore the existence of disabled persons. During my daughter's school years we had to physically lift her to upstairs classroom. When she was a child it was easy but as she grew older it became a very painful exercise. When my husband went out on official tours she could not go to school.

Aditi Panda, Parent, Bhubaneswar

A disabled woman must acquire a solid education, no matter what the cost. This provides access to dignity and intellectual pleasures, which are her rightful claim.

Sudipta Misra, Cerebral Palsy, Bhubaneswar

No standard rules for allotment of scribe creates a lot of problem for students who need assistance for writing. There should be a rule for selection and incentives for scribes, as done in Delhi and other states.

Lekharam Bhoi, VI, Banvomunda Panchayat Samiti Chairman, Balangir

IEV Volunteers need much more training to perform their duties properly towards CWSN.

Jihriga Oram, IEV Volunteer, Koraput

During examination seat allotments are done according to roll numbers with no consideration of our disabilities. My papa and Mama had to run from pillar to post, 30 minutes before my examination, because I was allotted a seat in first floor. No body listened, finally papa had to physically carry me up.

Sonali Harichandan, CP, Receptionist, Bhubaneswar.

When I was appearing in my +2 examination in Ravenshaw Junior College the invigilators refused me the extra 30 minutes allotted to students with disabilities by law. I met Principal and threatened to complain to higher authorities. Since then all students, in Ravenshaw, get the extra time. But most colleges do not allow this. There must be a campaign for this.

Vikramaditya Behera, VI, Students Union of the Visually Impaired, Keonjhar

When I was born, there were no services or support for people like me. When I first went to school, my hearing loss hadn't been detected. I had to learn how to read on my own, through necessity, watching people's lips when they read. At first I suffered discrimination from my teachers and from the other children. Despite many difficulties, I managed to finish school and then studied further finally becoming an architect. I now work in the chief architect's office. I am married to a deaf man. We have two children, both have no disabilities.

Minaxi Misra, Deaf Woman, Architect, Bhubaneswar

There is no match between one's education and employment.

Sriyarani Dei, OH, BPO Employee, Bhubaneswar

Everywhere I go they ask for experience, but without the chance to work, how can I have experience?

Rakesh Kumar Panda, OH, Nayagarh

Access to employment is a big headache for me because most employers are not ready to higher sign language interpreters.

Jatin Behera, HI, Bhadrak

...she submitted her resume...and was informed of an interview. She was in high spirits to attend the interview. However, the personnel on seeing her as a person with a disability cancelled the interview although her certificates were in order. She was dismayed and angry..... the personnel replied they could do nothing about it.

Rashmi Rekha Kindo's Friend about Rashmi who is OH, Sundergarh

Our children are brilliant with gadgets. They should be given work where they have to operate gadgets and they will do it to perfection.

Joshna Singh, Mother of Autistic Tanya, Bhubaneswar.

Of all the areas concerning disability, employment is the most neglected. The first Special Employment Exchange for the disabled was established in 1959 in Mumbai. Since then the government has set up 23 special employment exchanges, 55 special cells in regular exchanges, and seventeen vocational training centers. However, the present annual placement rate of placement is 4,000, and the total placements over the last 40 years may be as few as 100,000.

Dr. Satyanarayan Mishra, OH, Archivist, National Archives of India, Bhubaneswar

Parents of a disabled child should be counselled to help them realise that disability is not a punishment and that they are not to be blamed for it. Those parents who cannot afford to educate or care for their disabled child should get subsidy. When resources are scarce and parents have to make painful choices, they may reject a disabled child. The disabled child may not be seen as the most viable investment.

Kanak Mishra, Mother of Priyanka Mishra, Girl with Mental Retardation, Rourkela

I became disabled in 2009. My new condition left me unable to work, and I also had to start using a wheelchair – but one change I didn't expect was the constant abuse, the most humiliating being my maternal uncle trying to sexually abuse me. I'm an easy target – if my brakes are on I can't turn away – and, anyway, who would believe someone would molest a disabled neice. I don't often talk about it because I feel ashamed, something made worse by the reactions I received when I complained – like I am making it up.

Name hidden on request, OH, Erasama, Jagatsinghpur

Visually challenged girls like me are overprotected both at home and in school. When I came to Bhubaneswar, I could not travel by bus on my own. I also did not know how to ask people for information. Initially, I was very scared because we had never been allowed to leave the blind school alone, and at home someone always accompanied me.

Tuni Behera, age student (R.D. women's college), Cuttack

In our society a woman marries into the husband's family. She is expected to work for the family, i.e. physical work. Disabled women are not prime candidates for marriage. My daughters, both deaf, are unmarried and I am growing old. I am also a widow and I miss the helping hand of my husband who shared my worries and gave a shoulder to lean on. I feel sad to see my daughters without life partners and trying to cope up with loneliness by immersing themselves in job and house chores.

Santisudha Behera, Seema and Sonia's Mother, Bhubaneswar

People can find disability embarrassing but I don't really think about it like that. If I want to read a text message, I get my magnifier out on the train and read it. I don't really think about it until some child says, 'What's he doing, Mummy?' I think the problem is how the parent deals with it. Sometimes they go, 'Shhhh' and tell the child off for asking. I think it's sad when parents do that, instead of acknowledging that people do things in different ways. I'd like the parent just to say, 'Looks like he's trying to read something,' or, 'Maybe he needs something to help him read.'

Sambit Das, Low Vision, Manager Central Bank of India, Cuttack

My disability is a fundamental factor in the being that is 'me'. I do not want to deny this by calling myself 'a person with special needs' or 'a differently able person' or any other euphemism, nor do I want to deny the collective identity we have achieved ourselves. Therefore I am a disabled person, and proud of it.

Dr. Sruti Mohapatra, Spinal Cord Injury, Academician and Activist, Bhubaneswar



Executive Summary

Objective of the Study

1. To understand the socio-economic profile of PWD and prevailing obstacles on the path to mainstreaming and recommend strategies to bridge the gap.

Methodology

2. Keeping in mind the objective, the issues relating to disability were addressed through a qualitative multi-centered study.
3. Extensive literature review was followed by designing of questionnaires.
4. Structured questionnaires were developed to collect personal information from PWDs and ranking questions for public perception. They were piloted in Kendrapada and Nuapada district.
5. An 18 member strong team conducted a three month long field visit within Odisha.
6. A concerted effort was made to engage with the leaders of the disability movement. To that end, 8 focus group discussions and one state level consultation was held.
7. The team also undertook a series of key informant interviews with key stakeholders who are working within the disability sector.
8. An intense engagement for 16 months resulted in this document.
9. Sample Size was arrived at by using the sample size finder of Creative Research Systems (<http://www.surveysystem.com/sscalc.htm>). The sample size was 4152 with confidence level 99% and confidence interval of 2.
10. The percentage of population with disability in each district was calculated using 2001 Census figures. Similarly the male and female; and rural-urban % was calculated and accordingly the sample size was determined for each district.
11. In each district, three blocks were identified based on highest population and accessible geographical terrain. In Koraput, Nabrangpur and Raygada hilly terrains were avoided to save time.
12. From each Block, nine villages were randomly selected. Each of these villages were again selected on the basis of transport facilities available for return to base and density of population. Villages with close by houses were taken into consideration and villages with scattered settlements were

avoided. For ex. in Jajpur district Pakhara was selected whereas nearby Nakua Telara was avoided because of small and scattered settlements.

13. On reaching villages help was taken of villagers, ASHA karmis and AWW to identify PWD households. Reaching one PWD household provided knowledge of all PWDs households in village.
14. A total number of 4152 respondents were covered across 30 districts.
15. Respondents in working age group (25-55) were 2911. Student respondents (18-24) numbered 585. CWSN were 307, elderly 300 (age group 56 and above) and 49 were severely disabled.
16. There were 3510 respondents from rural areas and 642 from urban (includes cities and big towns).
17. 2311 respondents were male and 1841 were female.
18. Looking at the various categories of disabilities represented in our respondent group, 1252 were VI, 528 were HH, 1608 were OH, 400 were MR, 219 were mentally ill and 145 included multiple disability, autism, dwarf, cases of severe burn, old age disabilities, those bed ridden and hunchback.
19. All were Indian.
20. 96.4% of the respondents were Hindus, 2.4% were Muslims and 1.2% were Christians.
21. Odia is the mother tongue of 91% of respondents. Rest were Hindi, Urdu, Bengali and Telugu. Odia can be spoken and understood by all. English is understood by the educated few.
22. 65.4% of PWD households belonged to general caste. The rest were 14.5% SC and 20.1% ST.
23. 47.3% PWD lived in joint families and 52.7% in nuclear families. Average household size is 4.5 to 5.5.

Key Observations and Findings

Public Perception

24. A total of 1500 persons were interviewed.
25. The interviewee were doctors, lawyers, teachers, lecturers, engineers, government functionaries, political and social activists, businessmen, owners of various establishments, chief functionaries and lower level functionaries of various establishments and a collection of many other trades.
26. 92.5% of people were aware of disability but only 50% knew about learning disabilities.
27. Society considers slow or erratic learners as 'mentally challenged.'
28. Autism is not a much known fact. 32% knew the term Autism.
29. On being asked if society created barriers for PWD 54.5% people said yes, 39.1% said no, 5.2% said they do not know and 1.2% were unconcerned about the issue.
30. On being asked if PWD should be treated with extra care and favorably 40.5% agreed, 44.1% disagreed, 12.7% said they do not know and 2.7% said they would not care either way.
31. The responses to whether persons with disabilities should receive equal opportunities in terms of education was baffling. 28.1% agreed but 45.3% who did not agree gave conflicting opinions

which varied from 'no education needed', 'lot of support needed', 'more opportunities needed', 'send them to blind school', 'teach them at home' etc. It seems the question could not reach out to people.

32. In terms of employment of PWD there was an unfortunate no by 46.8% of people. 30.7% agreed, 13.9% did not know and 8.6% were unconcerned.
33. There was a strong denial towards sexual lives for PWDs. 57.9% strongly denied.
34. Regarding having PWD as neighbors 61.4% agreed, 36.7% refused and 1.9% did not respond.
35. When asked to categorize the various PWD, 32.1% wanted OH as neighbors, 29.3% VI and 28.1% HI. There was reticence in having mentally and developmentally challenged as neighbors. 8.5% did not want neighbors with disabilities.

Access

36. Out of 265 public buildings and facilities audited, 65% were completely inaccessible with a lot of architectural and environmental barriers; only 35% had some parameters of accessibility. There is no building or public facility which is truly 'accessible.'
37. Only 23.9% of built structures had a ramp. Of these ramps usability was further reduced as only 22.9% had appropriate width, 25.2% had non-slippery surface, 26.4% were clear of obstructions at both ends and only 21.9% were in identifiable location.
38. 20.2% buildings had an elevator. But its functionality was reduced as only 1.5% had accessible path to reach the elevator.
39. Only 5.9% buildings had separate toilet for PWD, of these 12.1% were identified by a sign. Only 29.3% of the separate toilets had enough space for moving around of the wheel-chairs.
40. Only 7% of built structures have communication facilities for the visually and sensory challenged persons.
41. In government institutions 95% toilets were inaccessible. 70%, 69% and 63% of offices do not have ramps, auditory signals and signage respectively.
42. In financial institutions 99% are inaccessible as most of them are in first floors of buildings. 90% do not have accessible ramps, 85%
43. 95% judicial institutions lacked ramps and access features. There was 100% absence of assistance in form of sign language interpreters and materials in braille or alternate formats.
44. Community places were inaccessible for PWD as most had steps, stairs and first floor mandaps. There was 100% absence of accessible toilets.
45. In judicial institutions 95% lacked ramps and access features. There was 100% absence of assistance in form of sign language interpreters and materials in braille or alternate formats.

Acquiring of Disability

46. Almost 64% of the disabilities in Odisha are acquired from birth or just after birth related complications.

47. 30% disabilities are due to accidents, serious illness during childhood and untreated injuries/ diseases. 3% is due to stress.
48. 3% disabilities are due to stress.
49. Acquiring of disability from birth or after birth forms a huge chunk of the total population. 4.1% cases were congenital or hereditary, 3.2% were pregnancy related, 28% due to various diseases (communicable and others), 38% due to polio, 2.4% due to eye infections and 3.1% due to ear discharges.

Awareness/Knowledge of Laws

50. 16 years after the passage of PWD Act, 1995, only 6% of PWD and their family were aware of the PWD Act.
51. The average awareness of other acts among PWD and their family is, 1.8% are aware of NT Act, 0.9% of RCI and 1.7% of Mental Health Act.

Government Entitlements

52. Only 48.8% of PWD possess a disability certificate. Ganjam tops the list with 70.5% and is followed by Khurda (68.4%) and Jagatsinghpur (58.9%).
53. In addition, FGD indicates that arrangements for disability certification do not always function well. Although there are fixed dates in district hospitals, only 10% percent adhere to it.
54. On an average only 17.4% of PWD get disability pension in Odisha.
55. The main deterrent to applying for ODP among those potentially eligible for disability pension is 'process too complicated', which put off about half of potential applicants among our respondents, with almost a further 10% citing 'don't know how' as the reason for not applying. The other aspect is a degree of fiscal rationing in aggregate numbers of disability pensioners as the schemes are state-funded mostly.
56. Though 34.4% are aware of the free distribution of aids and appliances yet only 18.6% are recipients. In age group 18-45, 31.1% PWD have aids and appliances.

Education

57. Literacy rate of persons with disability is at a dismal low with only 57.8%.
58. 42.2% PWD have no formal education, only 30.1% have passed primary school. 14.2% are class 8th pass, 9.1% are matriculate and 3.3% are graduates. 0.9% have a post graduate degree and 0.2% are technical degree holders.
59. Our research found most of the CWSN as remaining out of school. But the few who go enjoy school. 82% enjoy going to school. 54% said they had resource teachers, 11% said their schools had resource rooms, 28% participate in sports, 35% could access toilets and 18% are getting some form of scholarship.
60. Our interview of teachers found that 100% of them enjoy teaching but 92% expressed fatigue being overburdened. 89% said they have received training but only 12% expressed satisfaction

with the training. They felt it was short and there was no clarification of their doubts and questions.

61. 65% of the teacher respondents were satisfied with the learning teaching aids. 18.9% confirmed that their schools have resource rooms for CWSN.
62. 38% teachers consented that they have adequate knowledge of assistive and adaptive equipment.
63. 21.6% teachers expressed their having adequate knowledge about the environmental adaptations needed by students with physical disabilities. 24% of teachers have adequate knowledge about the disabilities specific characteristics and health care needs of students with physical disabilities.
64. Most teachers and parents were of the opinion that the CWSN should go to special school. The anxieties expressed by parents included among others, the lack of awareness of the school authorities on the issue.
65. As universities did not cooperate with our field researchers they were asked for information through RTI. It paints a grim scenario with no university except Ravenshaw having availed funds for making university barrier free.
66. No university has applied for HEPSN and TEPSE, funds from UGC except Utkal university, Bhubaneswar.
67. To the question 'what are the facilities being provided and what are the schemes implemented by the University for students with disabilities', all universities answered in negative. Same was the response to what are the special facilities available in your university hostel for the students with disabilities. The responses to 'do students with disabilities participate in sports and extra-curricular activities' reflected the grim apathetic situation in PWD live in our society.
68. The total number of students in our respondent group were 585. As against 35.7% who enjoy going to college 64.3% do not enjoy their college days.
69. 37.5% required physical access to building and transport. 26.4% had a need for braille material, 9.2% large print question paper, 4.3% audio material and 15.6% printed class notes. 7% had a mix of needs. Some required accessible laboratories, few personalized teaching, some requested more attention from teachers, few extra practical training hours and some coaching for entrance examinations.
70. Only 12.5% of the students received the educational aid that they required from college. While 61.7% replied in negative, 25.8% said they were unaware of the fact that college should provide them educational support.
71. While 9% of students receive some or other educational scholarships, 34% of the students do not receive any such scholarships. 57% of the students are unaware of the scholarships available to students with disabilities pursuing higher degrees.

Employment, Livelihood and Poverty

72. The situation is grim in Odisha with only 22.2% earning a living and the rest 77.8% surviving as dependents.
73. The earning cannot be termed as a 'earning' rather can be regarded as a supplement to family

income as the average income of a PWD is between 2000 to 3000 rupees per month.

74. Looking at the sectors of employment one finds an aggregation in small business and daily wage earning. 45% (291) run small business and 29% (191) are daily wage earners.
75. 13% are employed in various establishments. Of these only 29.7% were employed in regular sectors with credibility, 14% were engaged in NGOs and for 45% tuitions were source of income.
76. Small business included both individual proprietors and members of self-help groups. Of them 52.6% were owners of paan (betel leaf) shop. Grocery shops came next (13.4%) followed by 'others' which included self- help group activities.
77. The seed capital was mostly from 'own money', which was contribution of parents, family members, friends and personal savings. SHG groups were linked to banks. NHFDC loan came at a low 7.6%.
78. Of the 191 daily wage earners only 39% got work for 30 days. 17.5% earned for 20-25 days, 8% 10-15 days and only 0.7% worked for less than 10 days.
79. Rampant poverty among the PWD households is amply demonstrated by a measly 22.2% eking out a living and earning a very the poor income (on an average about 2-3000 rupees per month).
80. Non-profitability of businesses is a potent indicator of vicious hands of poverty on its way to gripping more PWD households. When enquired about having enough money to take care of family only 9.9% replied in the positive. 44.1% refrained from giving any answer, kept quiet, made a joke or looked away.
81. There is no or meager saving. Only 17.9% save. Mostly saving was utilized for health related activities or for repayment of loan.
82. Around 50% households covered in the study live in mud houses (Kacha house). During their discussion with our field researchers 80% of households living in mud houses said that they had no access to electricity which clearly indicate to the fact that the maximum percentage of households covered in the study are extremely poor and marginalized.

Health, Water and Sanitation

83. 82.5% PWD have access to health facilities.
84. In urban areas 45.8% PWDs visited district hospitals (or main government hospital), 9.9% went to PHC/CHC, 13.9% took medicines by consulting medicine shop owners/sellers and 7.7% went to private clinics and doctors. Among other forms, 2.1% Kabiraj (Vaidya), 9.1% homeopathy and 9.6% preferred medical camp by NGOs and charitable organizations, Unani, Siddhi, Reiki, Yoga, Pranayam, magnetic treatment, acupuncture and naturopathy. Faith healers provide healing to 2% of the population.
85. Among rural population only 13.8% PWD frequent district hospital. 37% visit PHC/CHC and 11.2% depend on Anganwadi workers/ ICDS Centre/ Mobile Van/ Dai and quacks. Few of them also directly go to the three medical colleges i.e SCB (Cuttack), VSS (Burla) and MKCG (Berhampur). Among other forms of health care 4.4% went to Kabiraj (vaidya/hakim), 7.8% to homeopaths and 4.9% to faith

healers. 11.8% depended on medicine stores and 1.1% only went to private doctors.

86. 86.4% PWD have access to access to a permanent source of water (only water not clean drinking water). The 'safety' of this water is a question to ponder on. The water stated as clean was on the basis of normal visibility.

87. Only 21.7% PWD use latrines. 70.4% go for open air defecation.

Marriage and Parenthood

88. It was found that only 36.5% PWD had life partners. All the rest (63.5%) lived a solitary life.

89. 78.2% PWD expressed the willingness to marry. Of the 21.8% who had no desire to marry comprised mostly of women.

90. Only 47% PWDs expressed the desire for parenthood.

Social Life and Leisure

91. Isolation in the family level was loud and visible. 41.2% PWDs were not involved in the house chores. 18.4% were assigned household cleaning and 6.9% washing of clothes. Only 1.2% were allowed to interact and serve guests and relatives.

92. PWD often are not part of the family dining. They mostly eat alone. The study found only 52.3% with access to dining.

93. 30.9% PWD watch TV.

94. 45.4% PWD visit fairs and festivals.

95. In colleges only 1.7% students with disabilities participate in sports and 2.9% in cultural activities.

Political Participation

96. Odisha recorded more than 66% polling in 2004 but the population with disability voted abysmally low with only 43.2% casting their vote. 56.8% did not vote.

97. The study found a clear reflection of apathy towards political involvement, awareness and interest among PWD.

98. Of those who cast their vote 38.2% did because they did not need any special arrangements. 23.8% pointed towards presence of ramps and ground floor accessible booths as their motivating factor, 23.5% were enabled by cooperative and sensitive officers in polling stations and 14.5% got help from political parties to reach polling booth, get their voters card etc.

99. There was clear indication that PWD want their political representatives to be empathetic to their issues. Only 9.7% said their political representatives were empathetic. 55.8% said a clear no and 34.5% made no comments.

100. 59.7% PWD could identify Navin Patnaik as the chief minister of Odisha.

101. 51% PWD could identify Manmohan Singh as the prime minister of India.

Law, Justice and Grievance Redressal

102. None of the courts have ramps; braille transcripts or audio books; or sign language interpreters.
103. RTI applications are being regularly violated. Swabhiman has filed RTI applications for information on disability pension recipients, MGNREGA jobs for persons with disabilities, LLC functioning but most remain unanswered.
104. Court of Disability Commissioner is defunct with their orders not being respected by government departments, mostly juniors are sent to represent the authorities against whom summon is issued and very rarely appearances are made by government authorities.

Networks

105. Networks and DPOs are building leadership among PWD.
106. They are sensitizing government, people representatives, administrator, human rights activists, philanthropists, and civil society about the various acts related with PWD.
107. They are raising voice collectively on violation of rights of PWD in the state.
108. There is no unity among the different leader or networks those who are working for disability. Most of NGOs are only working on projects and not for the cause.
109. Illiteracy among the PWD community and lack of communication facilities is pushing the movement back.



Chapter 1

Study Overview

The profiling of disability dynamics of Odisha draws its significance from the global initiative to address equity issues in disability. Over 600 million people – or approximately 10 per cent of the world's total population – have a disability of one form or another. Over two thirds of them live in developing countries. While their living conditions vary, they are united in one common experience: being exposed to various forms of discrimination and social exclusion. In all societies of the world, including countries which have a relatively high standard of living, persons with disabilities often encounter discriminatory practices and impediments which prevent them from exercising their rights and freedoms and make it difficult for them to participate fully in the activities of their societies. India and Odisha are not an exception to such disparity.

In the past, persons with disabilities suffered from a relative 'invisibility', and tended to be viewed as 'objects' of protection, treatment and assistance rather than subjects of rights. In pre-industrialisation era disabled people were either 'taken care of' in homes or taken care of by religious bodies in a charitable perspective which viewed people with disabilities as unfortunate and deserving of pity and care-taking. Then came the medical model, which viewed people with disabilities as needing to be 'cured'. It was followed by a rehabilitation perspective, which viewed people with disabilities as needing experts and professionals who can provide services to enhance their functioning. As a result of these two later approaches, persons with disabilities were excluded from mainstream society, and provided with special schools, sheltered workshops, and separate housing and transportation on the assumption that they were incapable of coping with either society at large or all or most major life activities. They were denied equal access to those basic rights and fundamental freedoms (e.g. health care, employment, education, vote, participation in cultural activities) that most people take for granted. These two models caused social isolation and created a huge gulf between PWD and mainstream society. The transition to the rights based approach started with growing awareness and several significant landmarks in dealing with the disabled both at the national and international levels. The Economic and Social Commission for Asia and Pacific (ESCAP) declared 1993 to 2002 as the Asian and Pacific Decade of Disabled Persons. In response, the Indian Parliament, guided by the philosophy of empowering persons with disabilities and their associates, enacted in the year 1995, The Persons with Disabilities (Equal Opportunities, protection of Rights and Full Participation) Act, 1995 followed by National Trust Act 1999. The office of Chief Commissioner for Persons with Disabilities has been established for monitoring

implementation of various provisions of the PWD Act 1995. The Government of India enacted the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act in 1999. The objective of this Act is to provide support to the creation of enabling climate for as much independence as is possible and to provide for assistive decision making wherever essential. A board has been constituted to discharge functions as enshrined in the Act. Prior to it, government had passed the Mental Health Act in 1987 and the RCI Act in 1992. The Rehabilitation Council of India Act was notified in 1992. This Act provides for regulating the training of rehabilitation professionals and upgrading the quality of professionals.

The years 2006-08 was very significant for disability rehabilitation sector. In February 2006, the MSJE released the National Policy for Persons with Disabilities. The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted on 13 December 2006 at the United Nations Headquarters in New York and came into force on 3rd May 2008. It was ratified by India in 2009. This gave way to the thinking that not only new initiatives and programs will be launched, but also programs and initiatives started during previous years will be strengthened, so that persons with disabilities get their rightful place in the society which is inclusive, and provided with equal opportunities.

Odisha which is one of the poorest states in India recognizes the inequity existing in the state. As per 2001 Census 1021331 PWD live in Odisha. In exercise of the powers conferred by sub-section (i) and Sub-section (2) of Section 73 of PWD Act, 1995, the State Government has enacted Persons with Disabilities (Equal opportunities, Protection of right and full participation) Orissa Rules, 2003 to carryout basic objectives of PWD Act, 1995 like guidelines for evaluation of various disabilities, constitution of State Coordination Committee and State Executive Committee, recognition of Institutions for persons with disabilities, appointment of Commissioner for Persons with Disabilities etc. besides implementation of provisions of national legislation like National Trust Act and Rehabilitation Council of India Act, 1992. Of the six national Institutes working in different areas, one, SVNIRTAR (Swami Vivekanand National Institute of Rehabilitation Training & Research), is located in Cuttack. This autonomous national institute conducts long and short term specialized courses to train professionals in physiotherapy, occupational therapy and prosthetic and orthotic engineering. Extensive infrastructure has been developed on teachers training in special education by establishing teachers training Institutions in collaboration with national institutions. TCTVH runs in collaboration with NIVH, Dehradun,

TCTD functions as regional centre of NIHH, Mumbai, and TCMH is run by Chetana, a Bhubaneswar based voluntary organization. Besides, state government has recognized institutions running courses like Bachelor in Audiology Speech Language Pathology, and Bachelor in Physiotherapy. SIDR in Bhubaneswar and DDRC at Khurda, Kalahandi, Sambalpur, Koraput, Ganjam and Kandhamal provide various kinds of rehabilitation services to PWD. MVSN, State channelising agency of NHFDC has been providing loans on concessional terms for undertaking self-employment ventures by PWD. With a view to forming SHGs of persons with disabilities for taking up group economic activities and wider coverage of identified population, Mission Kshyamata, functions in the state. One VRC is also based in Bhubaneswar. VRC functions under Ministry of Labor and Employment.

Since the state has maximum percentage of socio-economically disadvantaged population, the disparities among the different sections of population are quite prominent. The government aims to achieve equity for persons with disability. As a result of strong advocacy by PWD, government established office of the State Disability Commissioner in March 2010. In it started the 'Bhima Bhoi Rehabilitation Programme' and created the Directorate of Disability.

The development community largely fails to address the full range of rights and concerns of persons with disabilities in mainstream development work. The exclusion barriers and social and environmental challenges, which persons with disabilities living in poverty experience, need to be urgently addressed if PWD are to be included in society and are to break out of a vicious cycle of poverty and disability. It is necessary and important to run development activities designed to address the particular needs of disabled people through sector-specific projects. But at the same time, it is also vital to address disability as a crosscutting issue, and to consider the needs of all sectors of a diverse population in generic development projects, if the issues of concern to PWD living in poverty are not to remain as a side issue. All development staff should automatically consider and incorporate the rights and needs of PWD into the design and application of their work, as they do regarding other marginalized and discriminated populations. Against this backdrop, the profiling of persons with disabilities was conducted for developing equity strategy and actions to address disability equity issues. This will enable the state to develop an inclusive rather than welfare approach to service provision. It will also enable the state to develop training programs for service providers to identify barriers which persons with disability encounter when accessing programs and services and to develop strategies to minimise the impact of these barriers. The research work was carried out by Swabhiman.

Governments throughout the world have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities.

Stephen Hawking
Nobel Laureate
(World Report on Disability)



1.1 Objective of the Study

1.2 Methodology

1.3 Sample Size

1.1 Objective of the Study

To understand the socio-economic status of PWD and the prevailing obstacles on the path to mainstreaming.

1.2 Methodology

The issues relating to disability were addressed through a qualitative multi-centered study. A three month long field visit within Odisha was conducted by a team of field researchers who were second year students of MSW from local colleges of Bhubaneswar. Structured questionnaires were developed to collect personal information from PWD and ranking questions for public perception. They were piloted in Kendrapada and Nuapada district. A concerted effort was made to engage with the leaders of the disability movement. To that end, 8 focus group discussions and one state level consultation was held with PWD and DPOs. Focus groups were conducted on themes: (i) Government Entitlements; (ii) student issues (OH & VI); (iii) parents of autistic children; (iv) parents of mentally challenged children; (v) parity, stigmatization and social participation; (vi) young adults with disabilities; and (vii) women with disabilities. The focus groups were homogeneous and included members from all categories of disabilities, family members of persons with disabilities and service providers. In all, 8 groups were conducted with an average group size of 12 and state consultation had about 100 participants. The team also undertook a series of key informant interviews with key stakeholders who are working within the disability sector. A follow up visit of 30 days was done to fill up the gaps that emerged.

1.3 Sample Size

The appropriate sample size for a population-based survey is determined largely by three factors: (i) the estimated prevalence of the variable of interest – PWD population in this instance, (ii) the desired level of confidence and (iii) the acceptable margin of error.

The sample size was arrived at by using the sample size finder of Creative Research Systems (<http://www.surveysystem.com/sscalc.htm>). As per Census 2001 figures the number of male and females respondents in urban and rural areas of each district were calculated. In a population of 1021335 (Census 2001 – population of PWD in Odisha) the sample size was 4153 with confidence level 99% and confidence interval of 2 (Table -1 and Table-2).

The percentage of population with disability in each district was calculated using 2001 Census figures. Similarly the male and female; and rural-urban % was calculated and accordingly the sample size was determined for each district.

Table 1 : Sample size derivation (Census 2001)

Sl. No.	District	Total population with disability	% Population with disability	Number of respondents for study (calculated)
1.	Bargarh	42135	4.1	170
2.	Jharsuguda	15300	1.5	62
3.	Sambalpur	28283	2.8	116
4.	Debagarh	9892	1	41
5.	Sundargarh	41465	4.1	170
6.	Kendujhar	34728	3.4	141
7.	Mayurbhanj	54661	5.4	224
8.	Baleshwar	53752	5.3	220
9.	Bhadrak	44271	4.3	178
10.	Kendrapara	37408	3.7	153
11.	Jagatsinghpur	27161	2.7	112
12.	Cuttack	65567	6.4	265
13.	Jajpur	51730	5.1	211
14.	Dhenkanal	29188	2.9	120
15.	Anugul	29559	3	124
16.	Nayagarh	23799	2.3	95
17.	Khurda	62526	6.1	253
18.	Puri	57083	5.6	232
19.	Ganjam	93197	9.1	377
20.	Gajapati	13489	1.3	54
21.	Khandamal	18030	1.8	74
22.	Baudh	10086	1	41
23.	Sonapur	13431	1.3	54
24.	Balangir	32006	3.1	128
25.	Nuapada	13696	1.3	54
26.	Kalahandi	32421	3.2	132
27.	Rayagada	20605	2	83
28.	Nabarangpur	28104	2.8	116
29.	Koraput	26625	2.6	108
30.	Malkangiri	11137	1.1	45

Table 2 : Number of respondents (calculated using Census 2001 data)

Sl. No.	District	Rural Male PWD	Urban Male PWD	Rural Female PWD	Urban Female PWD
1.	Bargarh	86	8	70	6
2.	Jharsuguda	21	13	18	10
3.	Sambalpur	46	18	38	14
4.	Debagarh	21	2	16	2
5.	Sundargarh	60	33	51	26
6.	Kendujhar	67	11	55	8
7.	Mayurbhanj	110	9	98	7
8.	Baleshwar	112	14	84	10
9.	Bhadrak	91	11	68	8
10.	Kendrapara	82	5	62	4
11.	Jagatsinghpur	58	7	43	4
12.	Cuttack	110	43	82	30
13.	Jajpur	117	6	84	4
14.	Dhenkanal	63	6	47	4
15.	Anugul	61	10	46	7
16.	Nayagarh	52	3	38	2
17.	Khurda	81	66	63	43
18.	Puri	112	18	88	14
19.	Ganjam	166	37	144	30
20.	Gajapati	25	3	23	3
21.	Khandamal	38	3	31	2
22.	Baudh	21	2	17	1
23.	Sonapur	28	2	22	2
24.	Balangir	61	8	52	7
25.	Nuapada	26	2	24	2
26.	Kalahandi	6	56	5	65
27.	Rayagada	36	6	35	6
28.	Nabarangpur	58	4	51	3
29.	Koraput	48	10	41	8
30.	Malkangiri	22	2	19	2





Chapter 2

Key Observations

This report attempts to provide a situational analysis of the current social, economic and political status of persons within Odisha, by drawing upon responses from across the state, material gathered during key informant interviews, and focus groups discussions. The common perception, held by policy-makers and the public at large, is that disabled people and disability issues are viewed in terms of charity and welfare. Consequently, this viewpoint is a significant, entrenched factor that seriously militates against the social inclusion of disabled people within the country and Odisha also. This is manifested in a number of ways. Firstly, despite the disability discrimination legislation PWD Act (1995) being in existence since 1995 the awareness about the law is non-existent in the state. Secondly, the weak social protection network for disabled persons exacerbates the level of poverty that they encounter. Poverty has led to illiteracy, ill health and a social exclusion. Thirdly, positioning of disability in the Ministry of Women and Child Development has led to other department's complete exclusion of disability in all their programs.

There are many NGOs that do supply services to disabled people, but their geographical coverage is very limited and the quality of service is pathetic. As a consequence of the former, the vast majority of disabled people living in Odisha, particularly those living in rural areas, have no access to disability services. Again, this situation compounds the level of social exclusion that they experience. There are a plethora of disabled people's organisations (DPOs) that exist in Odisha. However, they have little understanding of a rights-based agenda or the principles of the rights based model of disability. Furthermore, there is a great deal of conflict that exists between these organizations, which has a serious negative impact upon their ability to effectively lobby the state government to implement a rights-based agenda to disability issues. In addition, the vast majority of the leaders of the disability movement are based in urban areas, and have little comprehension of the issues encountered by living in rural communities.

The basic PWD needs for social security, individual dignity and meaning full employment of PWD remains unmet. A close look at the access to public transport, toilets, hospitals, and government offices, public spaces like parks, educational institutions, and places of worship showed these are out of the reach of PWD in Odisha. Further all interventions are restricted to the physical access. The areas like education, teaching aids, books in Braille and interpreters for the hearing and speech impaired are still not available to large sections of the disabled. Similarly, in education of CWSN is mostly through isolated institutions which operate on a service and charity mode. Most of these institutions are not fully equipped also.

Disabled children are often victims of negative social perceptions, which, in addition to leading to their social isolation, have a harmful impact on their self-esteem, hence on their development.

*UNICEF Statement
United Nations,
New York, August 2002*



2.1 Public Perception and Societal Attitude

Disability limits access to education and employment, and leads to economic and social exclusion. But perhaps the greatest obstacle to participation and equity is the prevalence of deep-rooted negative attitudes on the part of non-disabled people in the family and community, as well as in Government and in the corporate sector. The shame some people associate with having disabled kin means that they are often hidden from public view – and as far as 'mainstream' development is concerned, forgotten. This is especially true of females, even those with minor disability being regarded as unmarriageable.

History is replete with examples of disabled people worldwide being ridiculed, killed, abandoned to die or condemned to permanent exclusion in asylums (Pritchard, 1963). Coleridge (1993) traces through history the killing of people with disabilities, beginning with the Spartans who killed disabled persons as a matter of law; the endorsement by Martin Luther to kill disabled babies because they were 'incarnations of the devil'; the English eugenicists who eliminated disabled people under the Darwinian evolution theory of the 'survival of the fittest' and the Nazi Euthanasia Programme under Hitler to exterminate disabled people as they could not make any contribution to society.

Much of the literature on disability in India has pointed to the importance of the concept of karma in attitudes to disability, with disability perceived either as punishment for misdeeds in the past lives of the PWD, or the wrong doings of their parents. As two Indian authors have put it, 'At a profoundly serious and spiritual level, disability represents divine justice'. At a more mundane level, persons with disabilities are traditionally perceived as somehow inauspicious. Much qualitative research has found considerable social marginalization of PWD in India, though most also acknowledge that the social status of the PWD family has an impact on their potential acceptance in society.

In this study, people were asked if they were aware of disability, categories of disability, if persons with disabilities were burdens, if society created barriers for PWD, if they would employ, if they would allow their children to study in same school, if they could be neighbours etc. A large proportion of the people interviewed expressed a very low level of knowledge on disability issues. They equally perceived PWD as a burden to society they live in. Most confirmed that they did not know much about current issues on disability. The harsh societal attitudes are likely also to segregate against the access of PWD to means of communication, such as inability to listen to radio or watch TV in the living room, in situations where PWD are confined in bedrooms and backyards in home settings. Lack of facilitated access to

educational opportunities to most PWD adversely impact on their level of knowledge on disability issues.

92.5% of respondents were aware of disability but only 50% new about learning disabilities. Respondents considered slow or erratic learners as 'mentally challenged.' Autism is not a much known fact (32%) (Table - 3).

Table 3 : Awareness of disability

Topics	Yes
Awareness of disability	92.5%
Awareness of learning disabilities	51%
Awareness of Autism	32%

On being asked if society created barriers for PWD 54.5% said yes, 39.1% said no, 5.2% said they do not know and 1.2% were unconcerned about the issue (Table-4). On next being asked if they should be treated with extra care and favorably 40.5% agreed, 44.1% disagreed, 12.7% said they do not know and 2.7% said they would not care either way (Table-5).

Table 4 : Society creates barriers for PWD

Statements	Number	%
Strongly Agree	818	54.5
Disagree	586	39.1
Don't Know	78	5.2
No response	18	1.2
Total	1500	100

Table 5 : Are PWDs treated fairly in society ?

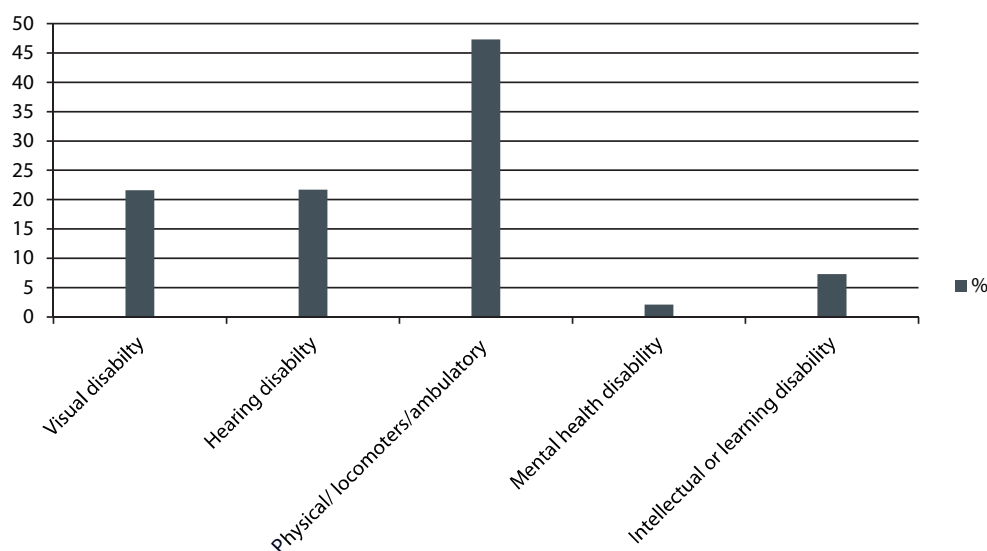
Statements	Number	%
Strongly agree	608	40.5
Disagree	661	44.1
Don't Know	190	12.7
No response	41	2.7
Total	1500	100

The responses to whether PWD should receive equal opportunities in terms of education was baffling. 28.1% agreed but 45.3% who did not agree gave conflicting opinions which varied 'no education needed', 'lot of support needed', 'more opportunities needed', 'send them to blind school', teach them at home etc (Table-6). It seems the question could not reach out to people. Or looking from another perspective, perhaps society is unable to accept children with disabilities as students or classmates!! This raises many questions.

Table 6 : PWD should receive equal opportunities in terms of education

Response	Number	%
Yes	421	28.1
No	679	45.3
Don't Know	400	26.7
Total	1500	100

This was followed by another question as to whether they agree that children with disabilities should attend the same schools as other children. The response was clear. People were comfortable with the orthopedically handicapped (47.3%), VI (21.6%), HI (21.7%) to read in same school. There was a complete reluctance in accepting mentally and developmentally challenged persons (Graph-1).

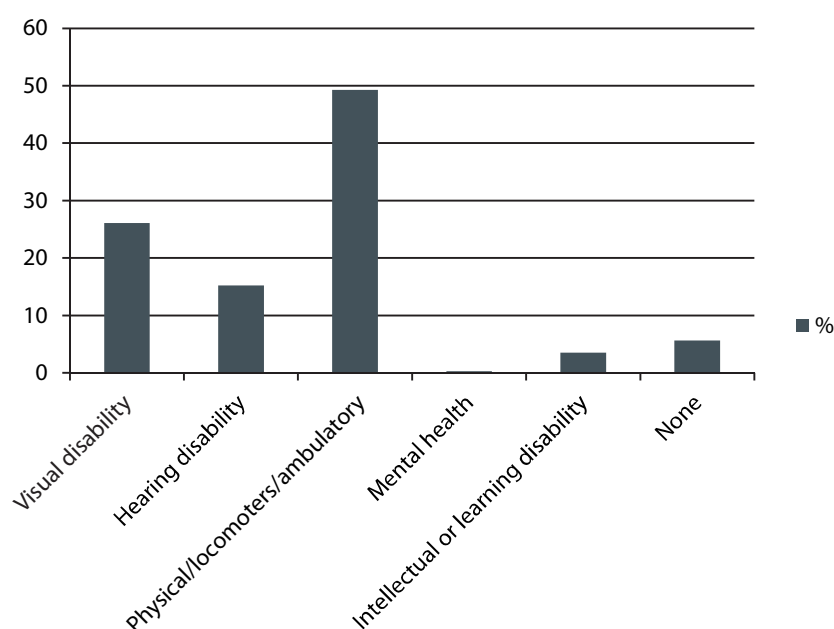


Graph 1 : CWSN to attend regular schools

In terms of employment there was an unfortunate no by 46.8% of people. 30.7% agreed, 13.9% did not know and 8.6% were unconcerned. When asked which category of persons were they willing to employ 49.3% said OH, 26.1% said VI, 15.2% said HI and there was complete reluctance to accept persons with mental and developmental challenges. 5.6% refused to employ any PWD (Table-7 and Graph-2). There is an overwriting necessity in educating employers about disability and convincing them that each prospective employee with disability has unique skills and abilities to perform as per the demands of the job.

Table 7 : PWD should receive equal opportunities in terms of employment

Response	Number	%
Yes	461	30.7
No	702	46.8
Don't know	208	13.9
No response	129	8.6
Total	1500	100

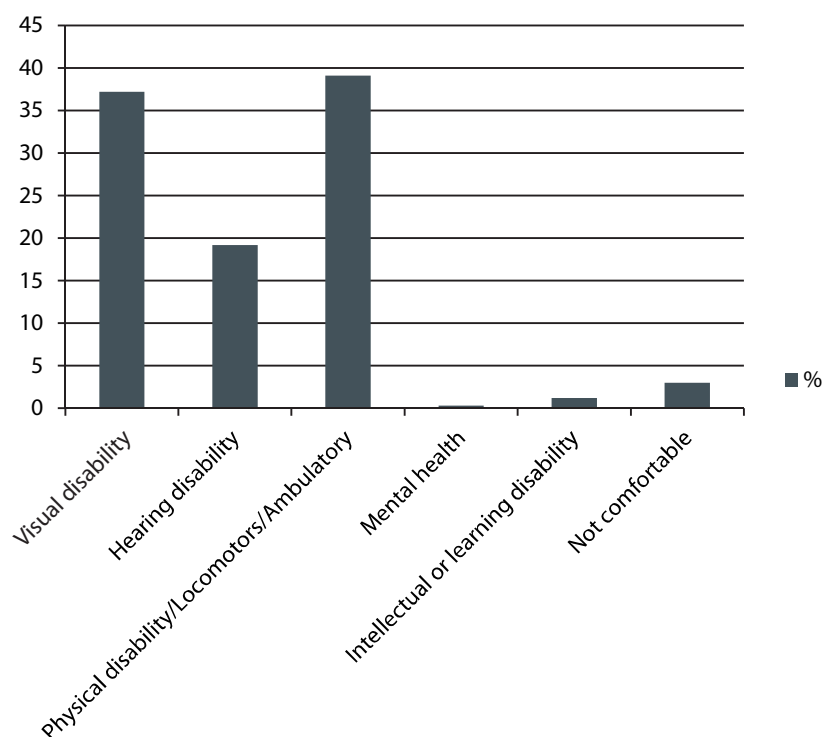


Graph 2 : Willingness to employ PWD

When asked if they would be comfortable with colleagues with disability 48.1% replied in affirmative. 40% said no, 6.9% did not know what to do and 5.1% were unconcerned (Table-8). However when enquired the category of PWD they would be comfortable with, the maximum votes were for OH (39.1%), 37.2% for VI, 19.2% for HI and almost no one wanted to have mentally and developmentally challenged persons as their colleagues. 3% said they would not be comfortable with any category of disability (Graph-3).

Table 8 : Willingness to have PWD as colleagues

Response	Number	%
Yes	721	48.1
No	600	40.0
Don't know	103	6.9
No response	76	5.1
Total	1500	100

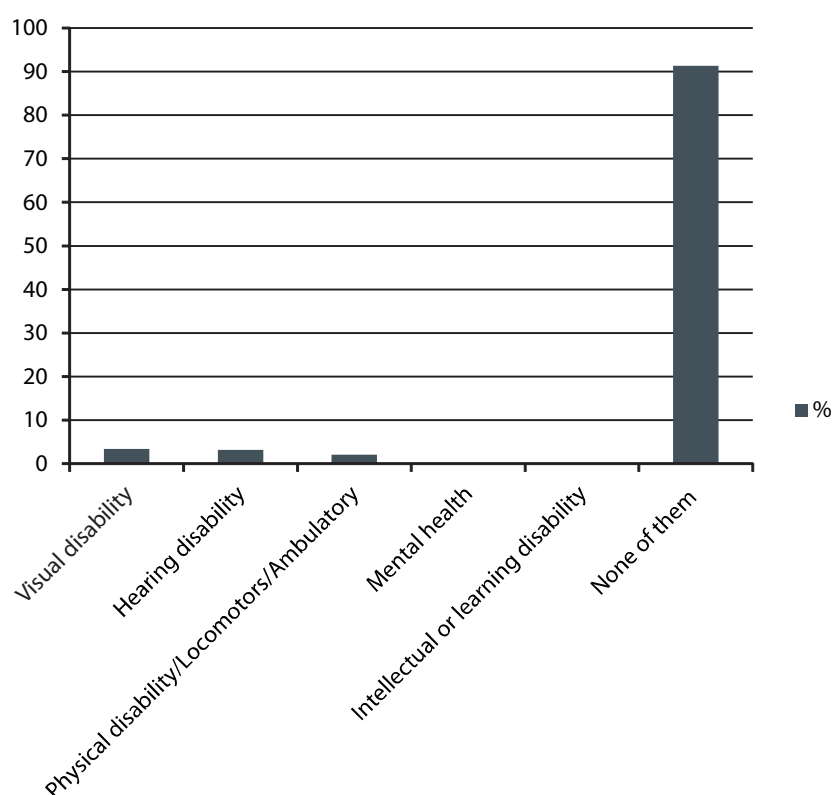


Graph 3 : Willingness to have PWD as colleagues

There was a strong denial towards sexual lives for PWD. 57.9% strongly denied. However 21.4% replied in affirmative. 15.6% were surprised at this question and said they do not know and 5.1% did not care (Table-9). When further probed to if any specific category of PWD could have sexual lives, 3.4% said VI, 3.2% said HI, 2.1% said OH and 91.3% said PWD should not marry or have sexual relationships (Graph-4).

Table 9 : Do PWD have a right to sexual relationships

Response	Number	%
Yes	321	21.4
No	869	57.9
Don't know	234	15.6
No response	76	5.1
Total	1500	100

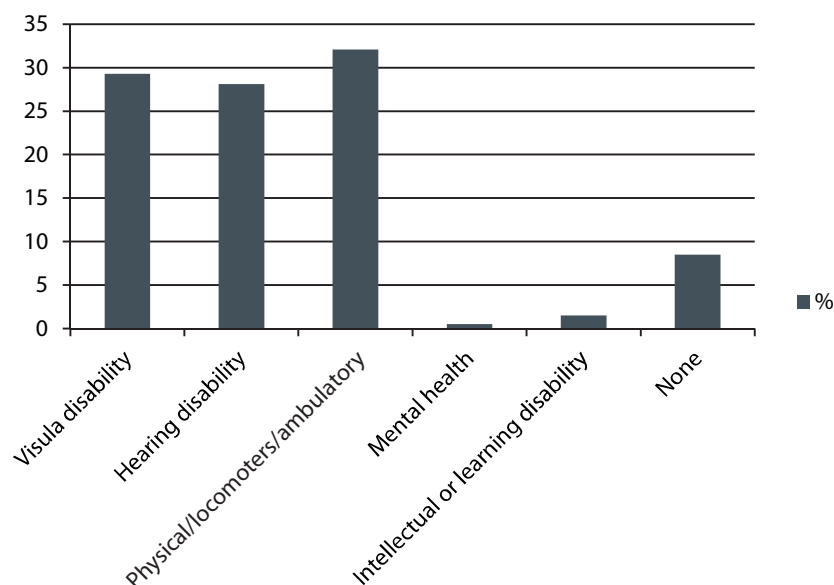


Graph 4 : Perception of sexual relationships by PWD

Regarding having PWD as neighbors 61.4% agreed, 36.7% refused and 1.9% did not respond (Table-10). 32.1 wanted OH as neighbors, 29.3% VI and 28.1% HI. There was reticence in having mentally and developmentally challenged as neighbors. 8.5% did not want neighbors with disabilities (Graph-5). With a growing metro culture, diversity and multi culturalism will soon replace conservative ideas. Acceptance of disability will then come in the ambit of accommodating diversity. The visibility of PWD in schools, colleges, workplaces, market places, cinema hall, social gatherings, in buses and trains will go a great length in allaying fears and reluctance towards PWD. Like all disadvantaged groups, PWD will also require the support of law to address discrimination and increase their visibility.

Table 10 : Level of comfort in PWD as neighbors

Response	Number	%
Yes	922	61.4
No	549	36.7
No response	29	1.9
Total	1500	100



Graph 5 : Level of comfort in PWD as neighbors

Recommendations

1. Government should launch information campaigns and sensitization programmes which raise awareness on the direct and indirect discrimination directed against PWD to prevent such discrimination.
2. To prevent the discrimination and exclusion arising from inaccurate and pejorative use of language the nomenclature and terminology suggested by this study (Annexure-5) should be employed in all state communications; transactions; rules; regulations; notifications and orders. Popularisation of this terminology should be an agenda in CSR activities.
3. Governments should launch and support stigma reduction programmes; mass education campaigns; information and technology linked dissemination programmes; and sensitization workshops on disability rights massively. These should address amongst others the medical fraternity; the family; government officials; political representatives; the media and the legal community; teachers and academicians industries, business and corporate houses.
4. Civil society and corporate houses must launch campaigns and organize workshops for their employees. These campaigns and workshops should
 - a. Promote values of inclusion, tolerance, empathy and respect for diversity
 - b. Stress on the value of a disabled life
 - c. Create awareness to respect the decisions made by persons with disability on office matters, within the ambit of their job specifications.
5. Government should launch legal literacy and information dissemination programmes on disability rights generally, and PWD Act more particularly.
6. For changing attitudes to disability it is particularly important for governments to work with persons with disabilities, NGO/DPOs, and communities. Celebration of International Day for Persons with disabilities should become a State and city event like Odisha day or Children's day. Instead of remaining confined to NGOs it should have larger visibility like Women's Day.

7. Disability decade should be planned by government with each year being celebrated with a theme. This will harmonize government, civil society and corporate houses to design respective activities in an organized manner. This will also provide a direction in addressing disability issues in a strategic manner and policies lead towards development.
8. Media must have dialogues with disability sector to create its features and articles in dispelling myth and changing mind sets. News reporting must go beyond coverage of rallies and functions to presenting disability as an issue of development and economy issue. For ex. budget analysis should include disability rights budgeting.
9. More number of documentary films should be produced using the experience and success stories of persons with disabilities.
10. Literature and cinema on disability, both fiction and non-fiction, to be promoted by both government and publishing houses.
11. Regular workshops and seminars should be planned by government for PWD to better understand their rights, laws on disability, understanding of inclusion and building their own positive image.
12. Inclusive art fairs, literary fairs and theater should be encouraged.
13. As part of CSR activities planned inclusive campaigns on employment and employability of PWD should be promoted.
14. Disability should be part of school curriculum.
15. Disability should become a subject in undergraduate, graduate and post graduate studies.
16. Universal design should become a course component of all engineering and architecture courses.
17. Disability, from the perspective of human rights, should be an integral component of medical syllabus.
18. All laws on disability, along with international instruments, should be taught to students of law.



Whenever we go to a bank, hotel, or even a mall, we see that there is hardly any facility that makes these public places accessible to disabled people. This is because most people are ignorant about providing special provisions for the handicapped.

***Mr. Justice I A Ansari
Justice, Gauhati High Court***



2.2 Access

Many of the rights provided for PWD in India cannot be realized without ensuring that the services to which they are entitled are accessible, and that barriers to access in their broader environments are reduced. Accessibility for persons with disabilities can mean many things, ranging from physical access to services and the built environment, to access to appropriate services such as adapted curriculum and rehabilitation services, to access to civil and political participation, including voting and the justice system. The focus of this unit is physical accessibility. The PWD (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, in its Chapter VII makes mention of creating accessibility in public buildings and transport (Box-1).

Box 1

Chapter VIII- Non-discrimination

44. *Establishments in the transport sector shall, within the limits of their economic capacity and development for the benefit of persons with disabilities, take special measures to-*
 - a. *Adapt rail compartments, buses. Vessels and aircrafts in such a way as to permit easy access to such persons;*
 - b. *Adapt toilets in rail compartments, vessels, aircrafts and waiting rooms in such a way as to permit the wheel chair users to use them conveniently.*
45. *The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development. Provide for-*
 - a. *Installation of auditory signals at red lights in the public roads for the benefit of persons with visually handicap;*
 - b. *Causing curb cuts and slopes to be made in pavements for the easy access of wheel chair users;*
 - c. *Engraving on the surface of the zebra crossing for the blind or for persons with low vision;*
 - d. *Engraving on the edges of railway platforms for the blind or for persons with low vision;*
 - e. *Devising appropriate symbols of disability;*
 - f. *Warning signals at appropriate places.*
46. *The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development, provide for-*
 - a. *Ramps in public buildings;*
 - b. *Braille symbols and auditory signals in elevators or lifts;*
 - c. *Braille symbols and auditory signals in elevators or lifts;*
 - d. *Ramps in hospitals, primary health centers and other medical care and rehabilitation institutions.*

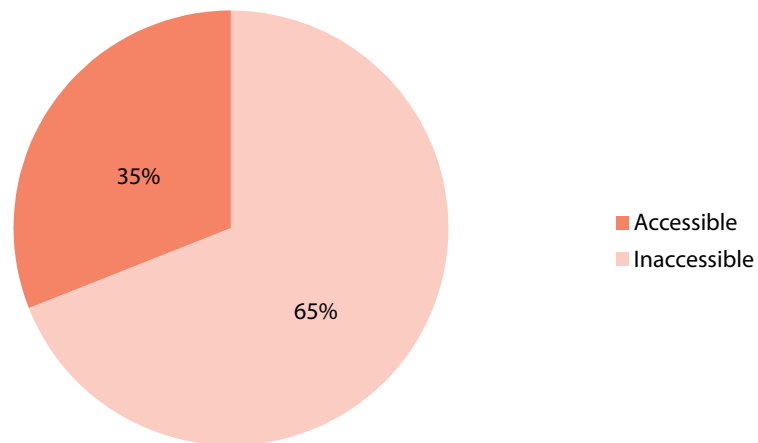
UNCRPD in its Article 9 mandates all state parties to create barrier free environment. Among others it specifically mentions physical access to enable persons with disabilities to live independently and participate fully in all aspects of life. The article states 'States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia: a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces; b) Information, communications and other services, including electronic services and emergency services.'

Despite legislation in India making it mandatory for all public buildings to be accessible to the disabled, hardly any have ramps or lifts that accommodate wheelchairs, signs in Braille, audio commands at traffic signals, or toilets that wheelchair-bound people can use. Buses and trains are virtually out of bounds for people in wheelchairs.

Research has proved that providing access facilities at the outset in any building adds no more than 2% to the overall cost while retrofitting existing building can be considerably more expensive since extensive work may have to be performed. Moreover, such features make buildings and other public spaces safer for everyone, not just the disabled. However, a survey amongst architects, builders and corporate firms reveals that currently, accessibility of buildings for disabled persons is a non-issue. Apart from hospitals and specialized institutions, few people involved in the planning and construction of buildings actively consider or give weightage to the architectural aspects of mobility for disabled persons.

After 16 years since the passage of PWD Act 1995 there has been little improvement in the status of access in Odisha. A study by Swabhimani in 2004 had found public and private institutions, buildings and built environments largely inaccessible and unfriendly to people with disability. 750 institutions and buildings within the 30 districts of Orissa had been audited, where 4265 access features and facilities were assessed. Out of 4265 facilities audited, 69% (3052) were inaccessible with a lot of architectural and environmental barriers, only 31% (1213) were found to satisfy some accessible parameter. In 2012, 65% of public institutions, including important Government offices, are not accessible (Graph-6).

In these 16 years when construction activities have almost doubled, it is a grim reflection of rampant inaccessible constructions by all private and government players. This in turn points to gross violation of the mandates of PWD Act 1995.

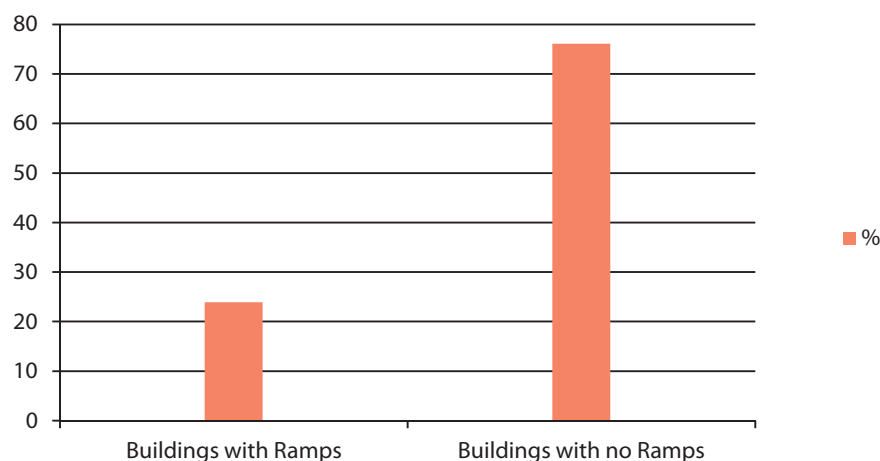


Graph 6 : Physical access in Odisha

One of the major issues in promoting access for persons with disabilities is that of institutional coordination. Particularly for the built environment, there are in most cases a range of line agencies and other local authorities responsible for infrastructure. This frequently results in no single agency considering itself responsible for making the built environment accessible, and/or problems with very partial accessibility in the face of uncoordinated action. The institutional issues in promoting access reflect deeper challenges of accountability. In this respect, the PWD Act itself is not of great use in terms of establishing clear lines of accountability for ensuring that accessibility standards are adhered to. A further important weakness in improving accountability has been the general lack of consultation with PWD themselves in prioritizing investments to promote access, and in monitoring access outcomes.

Only 23.9% of built structures had a ramp (Graph-7). Of these ramps usability was further reduced as only 22.9% had appropriate width, 25.2% had non-slippery surface, 26.4% were clear of obstructions at both ends and only 21.9% were in identifiable location (Table-11). 20.2% buildings had an elevator. But its functionality was reduced as only 1.5% had accessible path to reach the elevator (Table-12). Most elevators were situated on a surface which could be reached by climbing 3-5 steps. The other hindrance was narrow entrance.

Only in 6.7% of the elevators was the door opening enough wide. For the visually impaired 5.2% elevators had audible signals in form of voice announcements of floor arrival, door opening and closing; and for the hearing impaired 19.2% had visual signals in form of lights announcing floor arrival.



Graph 7 : Ramps

Table 11 : Features of ramp*

Features	%
PercentageAppropriate Width Ramp	22.9
Non Slippery Surface	25.5
Obstruction Clear Surface	26.4
Identifiable Location	21.9

* Of the 23.9% ramps

Table 12 : Accessible elevators*

Features	%
Accessible path	1.5
Audible signal	5.2
Visual Signal	19.2
Door opening/closing enough	6.7

* Of the 20.2% elevators

The floors and toilets increased the inaccessibility of most buildings which one could somehow manage to enter. Most new constructions, public utility buildings like museums, mandaps, malls etc. had slippery floors. Only 8.1% could be used by those walking with crutches and 11.5% were usable for the visually challenged (Table-13).

Table 13 : Floor surface and tonal contrasts

Features	%
Floors fitted with tiles	25.9
Accessible for crutches users	8.1
Accessible for VI	11.5

Only 5.9% buildings had separate toilet for PWDs. 12.1% were identified by a sign. Only 29.3% had enough space for moving around of the wheel-chairs (Table-14).

Table 14 : Accessible toilets

Features	%
Separate Toilet	5.9
Identified by sign	12.1
Enough width of door	75.4
Accessible basin	86.6
Enough space in toilet	29.3
Well lit room	89.8

We also looked at some specific service sectors, banks, post offices and hotels to find out the accessibility of service sectors. It turned out to be disappointing with the service sectors having not taken any proactive steps in the direction of accessible services. In each of these place persons with disabilities had to be dependent on family members or friends to use services like menu reading, availing ATM facilities or filling up a money order form (Table-15,16,17). All this despite notifications by Reserve Bank of India(RBI) and Ministry of Finance requiring ATMs and Online Banking to be accessible. In many states like Delhi, TN and metro cities banks nowadays are referring to financial inclusion. In Odisha too they need to look at accessibility in their branches as a way to build inclusion of persons with disabilities. In addition, they need to consider this as a way to meet their legal compliance, whereby they are not discriminating against any person.

Table 15 : Access in banks

Features	%
Identifiable counter	76.9
Accessible counter	0.0
Communication with HI	69.2
Room space for Wheelchair users	16.7
Guide strip for VI	0.0
Room space for PWD to fill forms	51.4

Table 16 : Access in post offices

Features	%
Identifiable counter	85.7
Accessible counter	0.0
Communicate with HI	14.3
Room space for Wheelchair users	23.0
Guide strip for VI	0.0
Room space for filling forms	17.0

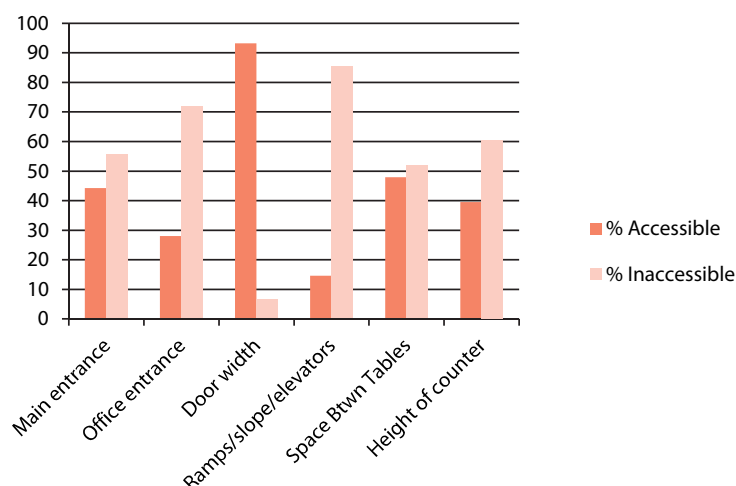
Table 17 : Access in restaurants/hotels

Features	%
Accessible Table	0.0
Communication with HI	72.7
Room space for Wheelchair users	51.0
Guide strip for VI	0.0
Menu in Braille	0.0

The other parameters were almost the same as in 2004 study (Box 2, 3 & 4). 93% of the public and private institutions have no communication facilities for people with developmental, speech, hearing and visual impairments. In the audited institutions, facilities like signage and auditory signals were virtually missing. Further, 80% have no ramps, railings, and adequate space between tables for unhindered movement of a wheelchair. The existing designs and location of water taps and toilets are inaccessible. 95% of the community places covered under the audit, such as public halls; marriage venues, temples, churches and mosques are inaccessible. This clearly reveals why persons with disabilities suffer exclusion from social life.

Box 2**Structural Access in Odisha (Swabhiman, 2004)****Status of physical access features in public & private institutions****Table 18 : Structural access**

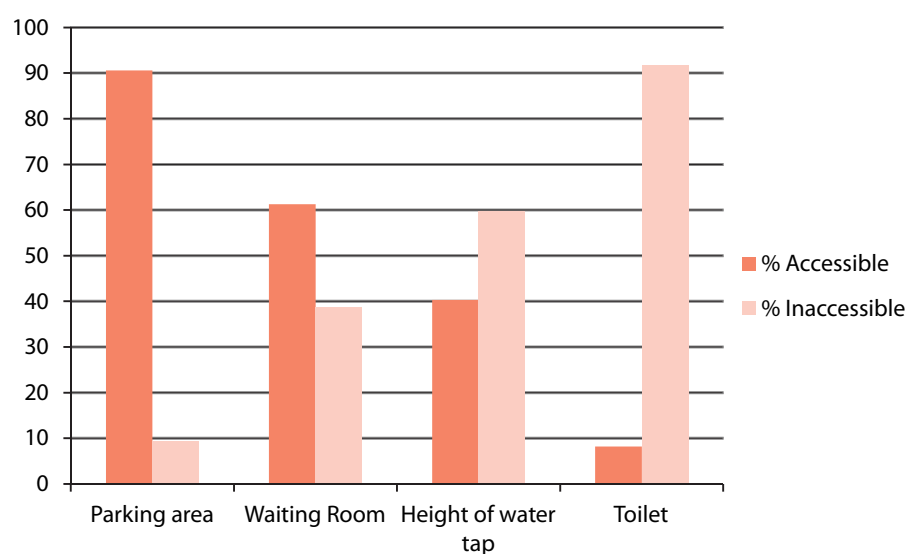
Access Features	% Accessible	% Inaccessible	Accessible	Inaccessible	Total
Main Entrance	44.3	55.7	192	241	433
Office Entrance	28.0	72.0	127	327	454
Door Width	93.2	6.8	400	29	429
Ramps/Slope/Elevators	14.6	85.4	63	369	432
Space Between Tables	47.9	52.1	180	196	376
Height of Counter	39.5	60.5	68	104	172

**Graph 8 : Structural access to public and private institution**

The structural access in this context has been used to refer to all architectural aspects of the buildings that accommodate both private and public institutions in Odisha. The audit results indicate that only 49.9 % are within access for people with disability. The situation of structural access to institutional buildings is made deplorable especially when the sequence of access is disjointed by existing gaps. For instance, the audit has revealed that even though the main entrance and door width may be within the accessible standards, they are rendered ineffective by the absence of ramps, slopes or elevators within the building. The absence of any one of these structures makes the entire building inaccessible to the physically challenged persons seeking to enter the building independently. Graph 2 demonstrates this case, where we found out that the door width and main entrance are largely accessible (at 93% and 44.3% respectively) but their use is ineffective due to the few number of ramps available (only 14.6%) in the entire state of Odisha. The height of the counters and the office entrance were largely inaccessible in most of these institutions as indicated by 60.5% and 72% respectively among all of the institutions audited (Table-18 and Graph-8).

Box 3**Utility Access in Odisha (Swabhiman, 2004)****Status of physical access features in public & private institutions****Table 19 : Utility access**

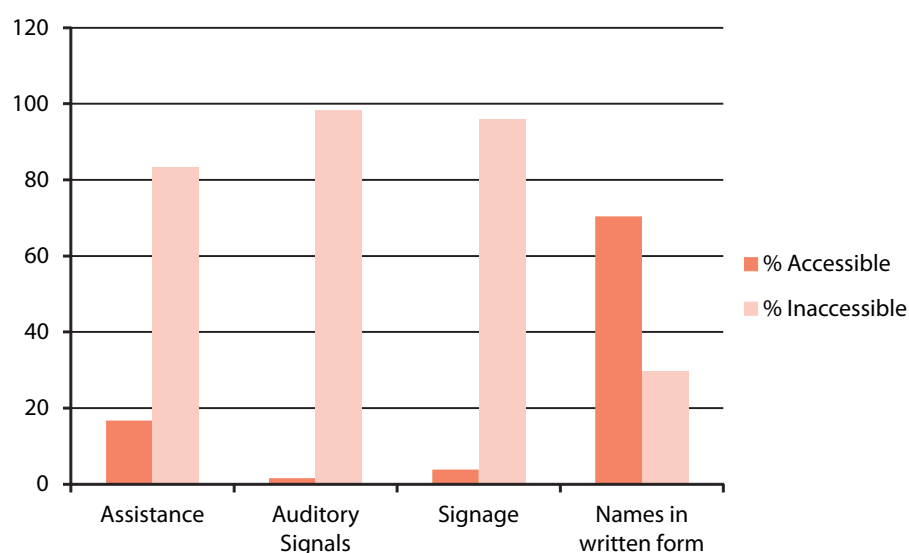
Utility Facilities	% Accessible	% Inaccessible	Accessible	Inaccessible	Total
Parking area	90.6	9.4	385	40	425
Waiting Room	61.3	38.7	228	144	372
Height of Water Tap	40.3	59.7	119	176	295
Toilet	8.2	91.8	35	393	428
Total	50.5	49.5	767	753	1520

**Graph 9 : Access to public utility facilities in public and private institutions**

The above graph reveals a deplorable situation on the status of public utility facilities that are vital to personal use by people with disability. These facilities are crucial components that empower PWDs to take an active role in public life. The audit results indicate that over 91% and 59% of toilets and water points respectively are completely inaccessible to people with disability (Table-19 and Graph-9). They lack structural components and size to allow access and use by people with disability especially those who are physically and visually challenged. Details regarding their actual situation will be discussed under the section on institutional based analysis. However the waiting room and parking area are some of the public utility facilities that were largely accessible, but mainly due to the natural gradient, not necessarily included in the original designs.

Box 4**Communication Access in Odisha (Swabhiman, 2004)****Status of physical access features in public & private institutions****Table 20 : Communication access**

Communication and mobility features	% Accessible	% Inaccessible	Accessible	Inaccessible	Total
Assistance	16.7	83.3	71	353	424
Auditory Signals	1.6	98.4	7	427	434
Signage	3.9	96.1	18	438	456
Names in written form	70.4	29.6	297	125	422
Total	22.6	77.4	393	1343	1736

**Graph 10 : Communication and mobility access in public and private institutions**

The audit results on the status of communication and mobility access features as shown in graph 4, indicates that majority of the institutional buildings in both public and private sectors in Orissa, are largely inaccessible owing to the decimal number of communication and mobility access facilities and assistance available on site. An average of 92.6% (assistance-83.3%, auditory signals-98.4% and signages-96.6%) (Table-20 and Graph-10) of the important communication access features are lacking in most of the institutional building and consequently rendering them completely inaccessible to people with disability in Orissa. The little assistance available is unreliable since they lack knowledge on basic disability etiquette and guidance skills. The existing labels on institutional buildings in written formats are largely insensitive to the special needs of people with varied disabilities. For instance, names written in brail for use by visually challenged persons are largely missing in most institutions.

Box 5

International symbols of disability



**The Information
Symbol**



**Access for
Wheelchair**



**Audio
Description**



**Audio
Description**



**Accessible Print
(18 Point or larger)**



Access for VI



Braille Symbol



**Telephone
Type Writer (TTY)**



**Sign Language
Interpretation**



**Assistive
Listening Systems**



**Volume
Control Telephone**



**Closed
Captioning (CC)**

Recommendations

1. State Government and municipal authorities must amend their building bye-laws to comply with the Gol guidelines and building code; and harmonizing it along with UNCRPD statuettes.
2. There should be clear sanctions in case of failure to comply with accessibility standards, and administrative clarity on official accountability in cases of failure to comply.
3. The office of chief architect to GoO should work towards benchmarking minimum national standards of accessibility to which authorities could be held accountable. These are a necessity under the new UN convention.
4. All new public buildings and built environment should be universally designed. An access audit of new buildings must be conducted prior to giving basic utility permissions like a telephone line, electricity and water connection.
5. There should be systematic involvement of disabled people and other civil society actors in monitoring of accessibility through requirement of access audits on all significant public infrastructural projects, including social infrastructure.
6. Accessible public transport, namely buses, auto rickshaws and taxis, must ply on the road by dozens. To start with one, accessible bus in the capital city and one each in district head quarters.
7. University and in-service training courses for architects, engineers and planners should include exposure to principles and practices of universal design and accessibility as a standard course element.
8. Engineers need to see the relevance of their technical skills in addressing disability access. The technical, problem-solving aspect of accessibility therefore needs to be emphasized when communicating with engineers, (rather than the social welfare aspect).
9. Public funds for the welfare of disabled people should also be used to support research on their access priorities, development of assistive devices for improving mobility of disabled people, implementing cost-effective universal design, and analysis of the impacts and costs of failure to provide accessible environments.



We are committed to nurturing a society that values the contributions of all of our citizens and residents, including the people living with disabilities. While people with disabilities are integrated into society as never before, I urge all governments across the globe that we must do more.

*Barrack Obama
President of United States, April 2011*



2.3 Population

The United Nations (UN) Disability Statistic's Compendium (DISTAT) noted that disability rates are not comparable across the world because of differences in survey design, definitions, concepts and methods, as the proportion of disabled people per national population varies between less than 1% in Peru and 21% in Austria (UN 1990). In 1981 UN/WHO studies estimated that on average 10% of all national populations were disabled. However in 1992, this estimate was modified to 4% for developing countries and 7% for industrialised countries (Metts 2000). There is no consensus as to which figures to use. The UN Development Program estimates a total global proportion of disabled people of 5% (Coleridge 1993), USAID at 10% and DFID at 4-7% (Yeo 2001). Depending on survey or census data different estimates are derived across the world with the United States census data estimating a disability prevalence rate of 20% in 2000 and a survey data estimating a 5% rate in China in 1987. (Mont 2007). Differences are also seen across member states of the WHO South- East Asian Region. In the 2001 and 2002 survey data, Bangladesh had the highest prevalence rates of 5.6% compared with a 1.5% rate in Timor-Leste. Census data also suggests that Thailand had a prevalence rate for disability in 2007 of 2.9% compared with a rate of 1.6 in Sri Lanka in 2001 (Table-21).

Table 21: Prevalence of disability in the Member countries of the WHO South-East Asia Region

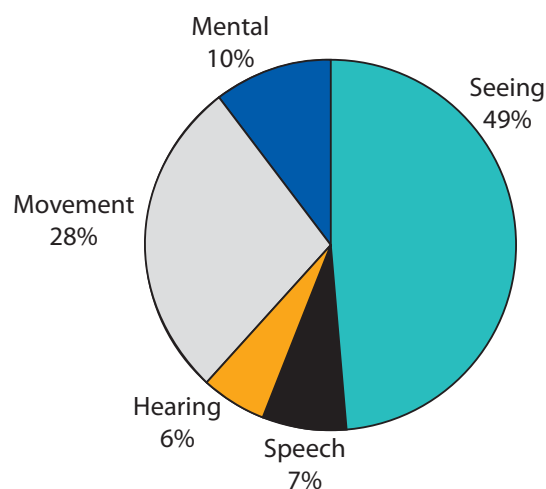
Country	Prevalence	Year	Source
Bangladesh	5.6%	2001	National Forum of Organizations Working With The Disabled Handicap International survey.
Bhutan	3.5%	2005	UN Economic & Social Commission (UNESCO) for Asia and the Pacific
India	1.8%	2002	UNESCO for Asia and the Pacific
Indonesia	21.3%	2007	Ministry of Health, Republic of Indonesia
Maldives	3.4%	2003	UNESCO for Asia and the Pacific
Myanmar	2%	2007	Ministry of Health
Nepal 1.6%	2001	UNESCO	for Asia and the Pacific
Sri Lanka	1.6%	2001	National Statistical Office
Thailand	2.9%	2007	National Statistical Office
Timor-Leste	1.5%	2002	UNESCO for Asia and the Pacific

Census 2001 reported that there are 2.19 crore persons with disabilities in India who constitute 2.13 percent of the total population (Graph-11). In Odisha the total population is 36,804,660, out of which 1021335 are PWD (Table-22).

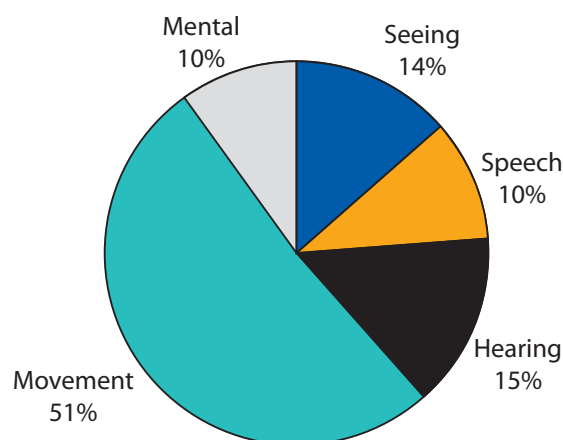
Table 22 : District-wise Population of Persons with Disability - Orissa 2001 (Source: Census 2001)

Sl.No.	Blocks	Total disabled population						In seeing			In speech			In hearing			In movement			Mental		
		Person	Male	Female	Person	Male	Female	Person	Male	Female	Person	Male	Female	Person	Male	Female	Person	Male	Female	Person	Male	Female
01	Bargarh	42135	23303	18832	21787	12080	9707	2829	1486	1343	3588	1875	1713	10163	5869	4294	3768	1993	1775	3768	1993	1775
02	Jharsuguda	15300	8293	7007	7792	4182	3610	964	498	466	1342	726	616	3713	2137	1576	1489	750	739	1489	750	739
03	Sambalpur	28283	15567	12716	14408	7855	6553	1925	1103	822	2294	1184	1110	7057	4059	2998	2599	1366	1233	2599	1366	1233
04	Debagarh	9892	5670	4222	5512	3292	2220	567	289	278	797	441	356	2271	1263	1008	745	385	360	745	385	360
05	Sundargarh	41465	22736	18729	18795	10227	8568	2843	1530	1313	4131	2147	1984	1457	6553	4904	4239	2279	1960	4239	2279	1960
06	Kendujhar	34728	19197	15531	15463	8409	7054	2883	1510	1373	3540	1867	1673	9170	5416	3754	3672	1995	1677	3672	1995	1677
07	Mayurbhanj	54661	29080	25581	25199	12828	12371	4306	2322	1984	5950	3123	2827	13917	7927	5990	5289	2880	2409	5289	2880	2409
08	Baleshwar	53752	30885	22867	21526	11681	9845	4424	2492	1932	6356	3469	2887	15314	9694	5620	6132	3549	2583	6132	3549	2583
09	Bhadrak	44271	25427	18844	24610	13514	11096	2716	1523	1193	3405	1807	1598	9232	6059	3173	4308	2524	1784	4308	2524	1784
10	Kendrapara	37408	21266	16142	17112	9001	8111	2283	1265	1018	3022	1738	1284	10459	6726	3733	4532	2536	1996	4532	2536	1996
11	Jagatsinghpur	27161	15701	11460	10708	5803	4905	1829	1050	779	2413	1276	1137	8409	5354	3055	3802	2218	1584	3802	2218	1584
12	Cuttack	65567	37936	27631	28800	15728	13072	4104	2320	1784	5115	2819	2296	18244	11694	6550	9304	5375	3929	9304	5375	3929
13	Jajapur	51730	30160	21570	24804	13705	11099	3318	1869	1449	4608	2585	2023	13184	8630	4554	5816	3371	2445	5816	3371	2445
14	Dhenkanal	29188	16850	12338	13573	7394	6179	1964	1097	867	2610	1499	1111	7698	4920	2778	3343	1940	1403	3343	1940	1403
15	Anugul	29559	16854	12705	16107	9003	7104	1938	1024	914	1910	1101	809	6963	4279	2684	2641	1447	1194	2641	1447	1194
16	Nayagarh	23799	13713	10086	12342	6582	5760	1399	777	622	1653	1000	653	5764	3765	1999	2641	1589	1052	2641	1589	1052
17	Khordha	62526	36295	26231	35550	19565	15985	3274	1922	1332	3936	2228	1708	12480	8210	4270	7286	4370	2916	7286	4370	2916
18	Puri	57083	31965	25118	31914	17045	14869	2777	1522	1255	4064	2220	1844	12118	7718	4400	6210	3460	2750	6210	3460	2750
19	Ganjam	93197	50122	43075	54708	27054	27654	6209	3562	2647	4411	2508	1903	20757	12733	8024	7112	4265	2847	7112	4265	2847
20	Gajapati	13489	6921	6568	6247	2985	3262	1151	540	611	1265	641	624	3913	2260	1653	913	495	418	913	495	418
21	Kandhamal	18030	9956	8074	9082	4821	4261	1085	604	481	1891	1066	825	4601	2708	1893	1371	757	614	1371	757	614
22	Boudh	10086	5553	4533	5287	2833	2454	820	456	364	838	447	391	2413	1442	971	728	375	353	728	375	353
23	Sonapur	13431	7604	5827	5556	3157	2399	1174	639	535	1318	693	625	4058	2406	1652	1325	709	616	1325	709	616
24	Balangir	32006	17287	14719	12870	6859	6011	2817	1492	1325	3191	1650	1541	10088	5752	4336	3040	1534	1506	3040	1534	1506
25	Nuapada	13696	7232	6464	6209	3167	3042	1306	685	621	1175	627	548	3728	2072	1656	1278	681	597	1278	681	597
26	Kalahandi	32421	17450	14971	16346	8704	7642	2649	1362	1287	2787	1499	1288	7621	4252	3369	3018	1633	1385	3018	1633	1385
27	Rayagada	20605	10520	10085	12934	6282	6652	1139	605	534	1337	703	634	3588	2054	1534	1607	876	731	1607	876	731
28	Nabarangapur	28104	14966	13138	17114	8921	8193	1699	888	811	2049	1109	940	5007	2819	2188	2235	1229	1006	2235	1229	1006
29	Koraput	26625	14360	12265	15800	8316	7484	1644	885	759	2078	1111	967	5033	2879	2154	2070	1169	901	2070	1169	901
30	Malkangiri	11137	6045	5092	5949	3158	2791	637	308	329	1041	542	499	2431	1427	1004	1079	610	469	1079	610	469
	ORISSA	1021335	568914	452421	514104	274151	239953	68673	37625	31048	84115	45701	38414	250851	153077	97774	103592	58360	45232	103592	58360	45232

There are many other statistics also like that of NSSO Sample Survey (Graph-12), survey by office of Chief Commissioner Disability, Gol and WHO findings which report higher percentage of the persons with disability in general population. The various estimates of prevalence rates of disability in various states significantly contrast with each other (Table-24). Obviously there is large regional variation within these estimates particularly due to the fact that definitions of disability vary. Census estimates are 3.8 times NSSO estimates (58th Round), but very low than estimates of World health Organization and United Nations according to which around 10 percent of population in underdeveloped and developing countries are disabled.



Graph 11 : Estimates of Disability Census 2001



Graph 12 : Estimates of Disability NSSO 2002

As per NSSO 58th Round data the number of disabled persons in Orissa is highest i.e. 2459 persons as against the national figure of 1755 persons per 1,00,000 persons. The National Sample Survey made its first attempt to collect information on the number of physically handicapped in the 15th round during July '59 to June '60. The enquiry was exploratory in nature and was confined to rural areas only. However, in the 16th round (July'60 - June'61), the geographical coverage was extended to urban areas. The subject was again taken up in the 24th (July'69 - June'70) and in the 28th (October'73 - June'74) rounds of NSS. The NSSO undertook a comprehensive survey of disabled persons in its 36th round during the second half of 1981, the International Year of the Disabled Persons. After a gap of ten years, a second survey on the disabled was carried out in the 47th round during July-December 1991 at the request of Ministry of Social Welfare, Govt. of India. Again after a gap of eleven years, the third survey on the disabled was carried out in the 58th round during July-December 2002 at the request of Ministry of Social Justice and Empowerment (MSJE), Govt. of India.

In NSSO 58th Round data (Table-23), compared to urban area of the state, the prevalence of disability in rural areas (1821 persons) is significantly high (2544 persons). Male and female comparison shows that the prevalence of disability among males (2586 persons) is much higher than the females (2330 persons). Odisha is also far behind the national figure per 1000 distribution of disabled persons of age 5 years and above by level of general education. When the national figure shows that 547 disabled persons per 1000 distribution are illiterate, in Odisha it is as high as 642 persons per 1000 distribution. Of the rest, maximum i.e. 210 are up to primary level, 96 are up to middle and only 52 are up to secondary level of education in Odisha.

Table 23 : Rural/Urban and Sex wise prevalence of various types of disabled persons in Orissa as per 58th Round of NSSO data

Prevalence of different types of disability in Orissa per 1,00,000 population, 2002									
Type of Disability	Rural			Urban			Rural + Urban		
	Male	Female	Person	Male	Female	Person	Male	Female	Person
Mental Retardation	129	71	100	136	127	131	130	78	104
Mental Illness	182	168	175	169	97	134	180	160	170
Blindness	253	287	306	148	248	197	303	282	293
Low Vision	241	270	255	117	199	157	226	261	244
Hearing Disability	642	563	603	467	393	431	621	543	582
Speech Disability	206	176	191	174	145	160	202	173	188
Locomotors Disability	1213	1173	1193	985	653	823	1186	1112	1149

Table 24 : Prevalence of disability in various states of India

Region	Reference	Major findings
Karnataka	Ganesh et al. (2008)	Prevalence = 6.3%. 80% of the disabled had multiple disabilities. Knowledge and occupation plays a major role as determinants of disability. Chronic medical conditions are also more common among disabled.
Karnataka	Pati (2004)	Prevalence rate = 2.02%, higher in 45-59 years age groups, higher in females (2.14%) than males (1.89%). Locomotor disability was the most common..
Karnataka	Kumare et al. (2008)	Prevalence of mental disability = 2.3%, more prevalent among females (3.1%) than males (1.5%), significantly higher among elderly people and illiterates.
Kerala	Mini (2006)	Prevalence rate = 2.7%. Highest number of visually disabled followed by movement disability. Literacy rate = 67% among the disabled people, otherwise the state highest literacy rate of 90.9%. The male-female gap in literacy rate of general population is 6.5 which widens to 15.8 among the disabled population.
Chandigarh	Singh (2008)	Prevalence rate = 4.8%, disability rate significantly more in aged 55 years or more (31%) compared to 25-54 years (5.4%) and <25 years (0.1%) ($p < 0.001$). Rates were higher in females compared to males ($p < 0.001$).
Delhi, Jaipur, Lucknow	ICMR (2007)	Disability rates in children below 6 years of age were 8.8 per 1000 in Delhi, 6.5 per 1000 on Jaipur & 12.6 per 1000 in Lucknow.

2.3.1 Category of Respondents

A total number of 4152 respondents were covered across 30 districts. All were Indian. 96.4% of the respondents were Hindus, 2.4% were Muslims and 1.2% were Christians. Odia is the mother tongue of 91% of respondents. Rest were Hindi (Nuapada, Nabarangpur, Sundergarh, Keonjhar, Mayurbhanj), Urdu (Bhadrak, Kendrapada), Bengali (Baleswar, Mayurbhanj, Keonjhar) and Telugu (Ganjam, Gajapati, Koraput, Malkangiri). Odia can be spoken and understood by all. English is understood by the educated few. 65.4% of PWD households belonged to general caste. The rest were 14.5% SC and 20.1% ST. 47.3% PWD lived in joint families and 52.7% in nuclear families. The household size varies between 4.5-5.5%.



In all countries, there is a shift in age of onset of disability towards later onset as maternal-child health systems improve, infectious diseases are controlled, and number of accidents rise. In India, data reveals that the highest rate of disability occurs at or shortly after birth, and the second highest in onset of age from the 50s to early 60s.

***People with Disabilities in India:
From Commitments to Outcomes,
World Bank Document (May 2007)***



2.4 Acquiring Disability

Most of the disabilities that occur in human beings occur in children. Though there are adults who suffer from disabilities that they acquire because of trauma and disease, the maximum number of the disabilities is got when a person is young or in the childhood time. The causes of disability can be broadly classified into three groups: genetic/hereditary factors, biological (including age-related) factors and accidents. There is some overlap between the categories as there may be more than one cause of disability: for example, increasing frailty may have contributed to an accident, which in turn may have caused or exacerbated a disability.

The major cause of the disabilities is the congenital problems. The congenital problems are those that affect a child when it is in the womb of the mother. These congenital problems can cause malformation or abnormal formation of the limbs and various other parts of the body leading to various disabilities. Some of the common deformities that are caused by the congenital deformities include those like club foot, phocomelia and other such conditions. Some of the congenital disabilities in the child may also be caused because of the teratogenic factors. This means that the mother may have consumed some medications for diseases when she was pregnant with the child. The use of certain medications can cause the child in the womb to be affected and may lead to disabilities and deformities. This is the reason for women who are pregnant to be very careful as to what they consume during the period of pregnancy.

Though many of the deformities are present right from the birth of the child, there are also some deformities that are caused by disease in the childhood. There are some diseases like polio that can affected the child in the young age and this too can cause various deformities in the limbs leading to disabilities. The nutrition or the lack of certain minerals and vitamins in the body can also cause the person to be affected by disabilities. Good healthy food is needed for the child to grow into a healthy adult without deformities. Trauma in the childhood period is another cause of deformities and disabilities in children.

Specific diagnostic preventive measures to reduce the incidence or severity of disabilities are being researched all across the world. New recommendations for worldwide treatment and prevention of developmental disabilities are continuously being developed. Today, there are improved ways to manage head trauma, asphyxia (lack of oxygen), and infectious diseases (e.g., polio and measles) to reduce their adverse effects on the brain.

Almost 64% of the disabilities in Odisha are acquired from birth or just after birth due to communicable diseases, pregnancy related, polio, ear discharge, eye diseases etc. 30% disabilities are due to accidents, serious illness during childhood and untreated injuries/diseases. 3% is due to stress. 3% people could not figure out the cause of their disabilities (Table-25).

Table 25: Causes of disabilities

Causes	Number	%
From birth	2463	63.51
Accident or Disease	1148	29.6
Stress	122	3.15
Not Known	145	3.74



Many of these have a strong relationship to poverty. Poverty is associated with higher incidence, prevalence and severity of disability, coupled with limited access to rehabilitation services. Disability also reduces the earning capacity, and increases the expenditure on care and rehabilitation. Evidence from a study (Rao, 2009) confirms that disability as a cause and consequence of poverty now needs to be brought to centre stage and the development community needs to reorder its priorities to put disability in the mainstream.

Acquiring of disability from birth or after birth forms a huge chunk of the total population. Early care can prevent a lot of this. 4.1% cases were congenital or hereditary, 3.2% were pregnancy related, 28% due to various diseases (communicable and others), 38% due to polio, 2.4% due to eye infections and 3.1% due to ear discharges (Table-26). Proper ante-natal and post-natal care can address almost 90% of the cases and significantly reduce the percentage of population with disabilities.

Table 26: Disabilities from birth or just after

Causes	%
Congenital	4.1
Complications During Labor / Pregnancy Related	3.2
Diseases	28
Polio	38.2
Eye Problem	2.4
Ear Discharge	3.1

Recommendations

1. The training (on job) of AWW to be strengthened and regularly refreshed so that she can identify the disability among children (deafness, mental retardation etc.) during her home visits and refer the case immediately to the nearest PHC or District Disability Rehabilitation Centre.
2. To sensitize and train ASHA to create awareness about preventing birth defects, as she is creating awareness on health and its determinants and mobilizing the community towards local health planning.
3. In addition to the nationally prescribed standard for the amount of incentive ASHAs must be given extra incentive to assessing new born for any birth defect.
4. JSY to incorporate disability into its agenda in a big way, allocate resources, as it focuses on the poor pregnant woman with special dispensation for states having low institutional delivery rates namely the states of Uttar Pradesh, Uttaranchal, Bihar, Jharkhand, Madhya Pradesh, Chhattisgarh, Assam, Rajasthan, Orissa and Jammu and Kashmir.
5. Cash assistance in JSY to be provided for a sign language interpreter, care-giver or any such requirement of the pregnant woman with disability.
6. A cadre of 'Sakhyamata Karmis' to be created (like ASHA karmis) to conduct EIP for children with suspected autism between 3 and 6 years on the basis of 'Analysis of Verbal Behaviour', 'Occupational Therapy' and 'Brain-Gym' guidelines.
7. Government to form a multi disciplinary team consisting of doctors, special educators, counselors, therapists and social workers to act as a nodal body on 'Pushtikar Diwas' to screen the moderate and severely malnourished children and children with growth faltering for risk of any disability.
8. Hospitals should be made to screen newborns to detect disabilities immediately after birth. Neonatal screening (organized examination of all neonates in order to diagnose specific disorders so that they can be treated) should be made widely available.
9. The Medical Council of India should ensure that all doctors are trained in disability.



The Persons with Disabilities Act was passed in 1995. However, even after 16 years, the various provisions in the Disability Act and awareness about rights, need and care of disabled persons remains dismal and the issue of accessibility remains a far cry.

*Times of India
(Nov 28, 2011)*



2.5 Knowledge of Laws

Knowledge of all the legislations enacted to protect the rights of PWD is essential to enable PWD to seek justice, safeguard their rights, and promote empowerment of self and fellow PWD. A clear understanding of legal rights and duties leads to sharing power equally, gaining full access to the means of development and to inspiring a whole generation of PWD to work together towards achieving equality and justice.

Over past two decades a considerable number of researches have been conducted to understand the extent of awareness about disabilities and related legal instruments, awareness and policies. Batra (1981) made an attempt to study awareness in general public in a study entitled, 'Social integration of the Blind.' Madhavan et al., (1990) conducted a study entitled, 'Mental retardation awareness in the Community.' Various studies have been conducted on Disability awareness and attitudes of young children in an integrated environment (Kobe and Mulik, 1995; Sherman et al, 1996; Mostert and Crockett, 1999-2000). Wolfson, (1984) conducted a study, 'Historical Perspective on Mental Retardation.' The study reviews research on Mental Retardation (MR) from a historical perspective with special focus on its definition assessment, prevention and amelioration. Verplanken et al., (1994) conducted a study entitled, 'Emotions and Cognition: Attitudes towards persons who are visually impaired'. Myths regarding the causes still continue to be held by the illiterate section of the society and where the educational level is low. All these studies revealed that there is lack of awareness in the community regarding various disabilities and laws for persons with disabilities, their rights and role in society.

Social support network and social resources play a leading role in development of PWD. For them to have a clear understanding becomes obligatory for the development of the population of the disabled. Social resources in Indian context can be classified under four categories – Parents and care givers, community, local governing bodies, Panchayati Raj institutions NGOs and other institutions working for PWD (Thomas, 2006). This sector, as per our study, was very minimally aware of disability laws and legislation as spreading awareness about disability legislations has not been a priority for government. The PWD Act 1995 briefly mentions 'awareness' in chapter IV (Box-6) with reference to prevention and early detection. There is no mention of awareness of the Act itself among the masses. Lack of awareness is one of the key factors behind non-availing or less availing of government facilities and services being provided.

A paradoxical situation thus victimizes a PWD, where poverty aggravates disability and disability in turn increases poverty. And the situation becomes more unfavorable with lack of knowledge, awareness and literacy.

Box 6**Chapter IV- Prevention and early detection of disabilities**

25. *Within the limits of their economic capacity and development, the appropriate Governments and the local authorities, with a view to preventing the occurrence of disabilities, shall-*
 - e. *Sponsor or cause to be sponsored awareness campaigns and is disseminated or cause to be disseminated information for general hygiene. Health and sanitation.*
 - g. *Educate the public through the pre-schools, schools, primary health Centers, village level workers and anganwadi workers.*
 - h. *Create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted.*

UNCRPD in its Article 8 focus only on awareness-raising. It makes it mandatory for states parties to undertake to adopt immediate, effective and appropriate measures to raise awareness throughout society, including at the family level. It also speaks about promoting awareness-training programs regarding persons with disabilities and the rights of persons with disabilities.

The study brings to the fore the fact that information, and therefore the power of knowledge and empowerment, has been conspicuous by its absence in Odisha.

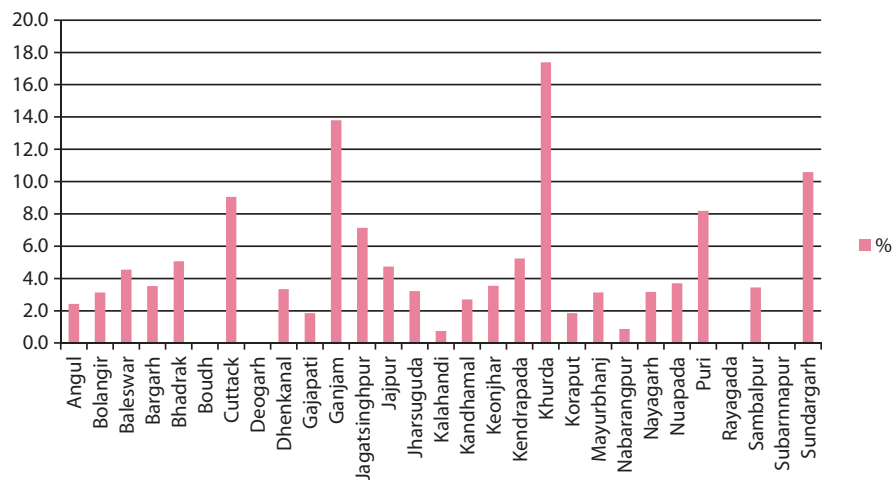
2.5.1 Level of Awareness

A key ingredient of effective implementation is awareness. 16 years after this landmark legislation only 6% of PWD and their family were aware of the PWD Act. The average awareness of other acts is dismal – 1.8% are aware of NT Act, 0.9% of RCI and 1.7% of Mental Health Act (Graph-14). The highest awareness of the PWD Act is in Khurda district (17.4%) followed by Ganjam (13.8%), Sundergarh (10.6%), Cuttack (9.1%), Puri (8.2%) and Jagatsinghpur (7.1%). Boudh, Deogarh, Raygada and Sonpur, at the bottom with no awareness, need more focused information outreach to the PWD households themselves (Table-27). The awareness of RCI, NT and Mental Health Act also remains dismally low (Graph-13).

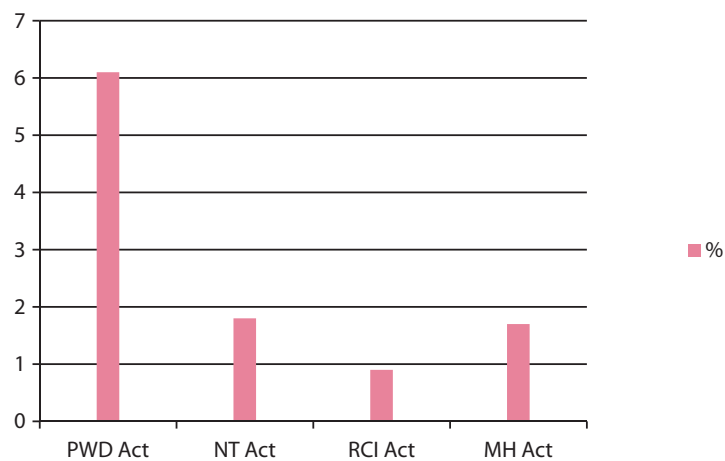
Very few PWD are aware that Article 14, 15, 16 and 21 of our Indian Constitution depicts about providing equal liberty, integrity and dignity to all the citizens. With lack of awareness of laws, potential as well as ambition of PWD, to develop as an independent individual takes a back seat. The attainment of equal opportunities and inclusion thus gets thwarted.

Table 27 : Awareness of PWD Act among persons with disability in Odisha

Sl. No.	District	Number	%
1.	Angul	3	2.4
2.	Bolangir	4	3.1
3.	Baleswar	10	4.5
4.	Bargarh	6	3.5
5.	Bhadrak	9	5.1
6.	Boudh	0	0.0
7.	Cuttack	24	9.1
8.	Deogarh	0	0.0
9.	Dhenkanal	4	3.3
10.	Gajapati	1	1.9
11.	Ganjam	52	13.8
12.	Jagatsinghpur	8	7.1
13.	Jajpur	10	4.7
14.	Jharsuguda	2	3.2
15.	Kalahandi	1	0.8
16.	Kandhamal	2	2.7
17.	Keonjhar	5	3.5
18.	Kendrapada	8	5.2
19.	Khurda	44	17.4
20.	Koraput	2	1.9
21.	Malkangiri	0	0.0
22.	Mayurbhanj	7	3.1
23.	Nabarangpur	1	0.9
24.	Nayagarh	3	3.2
25.	Nuapada	2	3.7
26.	Puri	19	8.2
27.	Rayagada	0	0.0
28.	Sambalpur	4	3.4
29.	Subarnapur	0	0.0
30.	Sundargarh	18	10.6
	Total	249	6.0



Graph 13 : Awareness of PWD Act among PWD



Graph 14 : Awareness of laws for disabled among PWD

The onus of implementation of the laws along with creation of adequate awareness, relating to disability, rests largely on the Government and its various entities at the Central and State level. Much needs to be done in the area of implementation of the disability enactments. There is a great need for holding more training programmes to meet the acute shortage of rehabilitation professionals. And many of the authorities themselves need to be sensitised about disability issues.

In general, it is lack of awareness about disability laws that often forces persons with disabilities and their families to live in isolation - in their own ghettos. Unaware, they are powerless to take benefits of the existing government facilities. Disability then becomes a 'problem' of just the person and his family. This lack of community action and support becomes a big hurdle in providing an enabling and equitable environment to grow and prosper.

Box 7

Awareness initiative 'Badhte Kadam'



The Telegraph

24 PAGES BHUBANESWAR SATURDAY 05 NOVEMBER 2011 XXOE www.telegraphindia.com

Badhte Kadam Against Disability

Our Correspondent

Bhubaneswar, Nov. 4: Saroj, a physically challenged boy, could work out solutions for chemistry problems in seconds. But it wasn't long before disability came in the way of his passion. The tables and the shelves in the lab were placed too high for him to access. He was forced to forego his passion and take an arts subject.

Most handicapped students in the state are forced to take arts for the absence of disabled-friendly labs. To create awareness about the rights of disabled people, Badhte kadam, a campaign by the National Trust under the ministry of social justice and empowerment was launched at the L. V. Prasad Eye Institute here. The campaign, flagged off by minister of culture Prafulla Samal would see young teams hitting roads, conducting awareness programmes at different locations.

Photo and poster exhibitions, display of aids and appliances used by the disabled, talent hunt, essay writing, art competition and signature campaigns will be organised as part of the campaign. Last year, the Badhte kadam was organised in eight coastal districts of the state. This year, it will reach out to 10 more districts.

The campaign will conclude on December 2, a day before the World Disability Day on December 3. "The campaign not only aims at making all sections of society aware of the plight of the handicapped people but also boosting the morale of the disabled. It will also help people with disability live with as much rights and responsibilities as any normal person," said coordinator of the state chapter of National Trust Sanyas Behera.

Box 8

Awareness initiative 'Get Yourself Counted'



BENNETT, COLEMAN & CO. LTD. | ESTABLISHED 1838 | TIMESOFINDIA.COM | BHUBANESWAR NATIONAL | TUESDAY, FEB 01, 2011 | PAGES 22 | PRICE ₹ 3.50

THE TIMES OF INDIA

Census 2011 and Disability

The journey to get proper enumeration of people with disabilities in Census 2011 started some year and a half back. This journey has seen big achievements like the question getting revised, the question being moved up, dedicated modules on disability for trainers and enumerators, and a slot on disability in the training of trainers and enumerators. However, the two big challenges in this campaign were/are: the enumerator actually asking the question and the respondent truthfully answering the question.

There are 270,000 enumerators and some 70 million people with disabilities! A humongous task! While efforts to train enumerators have been addressed to a large extent by active role of NGOs, the bigger challenge now is to make people with disabilities and their family and friends aware of the importance of answering this question. With increased awareness, even if an enumerator were to not ask the question on disability, the respondent can be alert and ensure that the question is asked and responses filled up. National Centre for Promotion of Employment for Disabled People (N.C.P.E.D.P.) along with its partners in various States and Union Territories has been actively trying to raise awareness on the issue. For a resource crunched civil society this is a mammoth task in a country of India's size. Here is a look at the strategies used.

N.C.P.E.D.P. along with its partners organised State Consultations on Disability and Census 2011 in Karnataka (August 31, 2010 in Bengaluru); Tamil Nadu (September 3, 2010 in Chennai); Andhra Pradesh (October 5, 2010 in Hyderabad); Uttar Pradesh (January 19, 2011 in Lucknow); and Gujarat (January 30, 2011 in Ahmedabad). Another one is now due in Bihar (February 7, 2011 in Patna).

In Tamil Nadu, Disability Legislation Unit (D.L.U.), South under Vidya Sagar is leading the campaign. Awareness rallies are being planned on February 2. Besides that, local cable television channels are being tapped to spread the word and a one minute ad film is being planned to be aired. A video on the issue in Sign Language has been made and C.D.s of it are being distributed. This has also been uploaded on YouTube.

Another State where tremendous work has happened is Orissa. Swabhimani, led by Dr. Sruti Mohapatra is undertaking several activities to spread awareness among all stakeholders. Orissa is an example in government and NGO partnership. Twelve young volunteers travelled across the length and breadth of Orissa to talk, discuss, answer questions and also appeal for accurate enumeration of people with disabilities.

A State level seminar on the issue was organised on January 18. It was followed by 30 district level seminars.

A film on 'Get Yourself Counted' has been made for regional language television channels. Swabhimani is also in touch with radio stations to air interviews of Dr. Mohapatra on this issue. They are also getting the issue covered on television talk shows, among other things. Handbills, posters, and leaflets in Oriya are being distributed in villages and to enumerators.

Swabhimani is also collaborating with various Government departments to spread awareness – from panchayat leaders to anganwadi workers to self help groups. Encouraging reports also streamed in from Jammu and Kashmir. A rally was organised under the leadership of our partner, Javed Ahmed Tak in Srinagar on January 4. He wrote to all stakeholders, including the Governor and the Chief Minister seeking support. Javed is also in touch with Doordarshan and All India Radio (A.I.R.). A pamphlet in Urdu is being distributed.

Although positive news keeps coming in from several States, there are still a few missing links. The North East seems to have lagged behind from the rest of the country. The difficulty of terrain and lack of reach of national media in that part of the country, in addition to the lack of proper awareness activities might not spell well for the sector and this campaign.

However, what has been most heartwarming is the way the disability sector has joined hands to take this campaign forward. There is a pronounced increase in awareness levels and enthusiasm among the stakeholders than the last time around. Hopefully, this will translate into increased numbers.

2.5.2 Source of awareness

When enquired about their source of information of various laws, social worker, got the maximum response followed by fellow PWDs and NGOs. Social workers included in its definition Anganwadi Workers, Community Level Workers of NGO, ASHA Karmi, IED Volunteers etc. NGOs included in its definition both organizations and individual disability activists; distribution of awareness material, camps and networks of PWDs. Others included VRC, Hospital, Politicians, Documentary Film, MVSN, NHFDC, SVNIRTAR, public meeting, public programs covered by media (of 3rd December), Rajiv Gandhi Foundation, Eye camp, PRI members, govt. servants, teachers (Table-28). The findings point not only to a general need for raising awareness of the rights of PWD (and suggest that greater reliance on non-governmental channels of information dissemination may be worth considering), but also the need for more focused information outreach to the core target group of PWD households themselves.

Table 28 : Sources of information of PWD Act

PWD Act	Number	%
Fellow PWD	52	20.88
Social Worker*	88	35.34
NGO**	31	12.45
DSWO	22	8.84
Medical Board	19	7.63
Newspaper & Radio	19	7.63
Family & Friends	6	2.41
Villagers	5	2.01
Others***	7	2.81
Total	249	100

* Anganwadi Workers, Community Level Workers of NGO, ASHA karmi, IED Volunteers

** NGO Activities, Awareness Material, Camps, Network of PWDs

*** VRC, Hospital, Politicians, Documentary Film, MVSN, NHFDC, NIRTAR, Public Meeting, 3rd December Program, Rajiv Gandhi Foundation, Eye Camp, PRI Members, Govt. Servants, Teachers

Recommendations

1. Laws to be translated to simple Odia language with plenty of pictures and to be distributed across the state in huge volumes (10 million).
2. Government officials, all cadres, must be refreshed on laws annually.
3. Law department must have a budgetary allocation for legal aid for PWD.
4. Appointments of disability officers in all courts to provide all required support to judges, lawyers and PWD.
5. Appointments of sign language interpreters in all courts.
6. Newspapers, radio and television to have fortnightly slots for dissemination of disability laws.
7. Medical boards to have a disability law awareness programs for waiting PWD.
8. Law syllabus must have four laws for PWD and UNCRPD in undergraduate, graduate and post graduate courses.
9. Initiatives like 'Badhta Kadam' and 'Get Yourself Counted' should be planned in more numbers of various issues (Box-7 & 8)

Voices

People were not aware of laws in rural areas. So awareness should be created at Panchayat level.

Suresh Choudhry, OH, ex Sarpanch, Kalahandi

PWDs were not aware about their entitlements. It was only in the third year of my BCA program that I came to know about Banishree scholarship. Government must create an awareness drive on PWD Act and entitlements in all colleges and universities.

Deepak Das, OH, Student, Ganjam

Regulations are abundant here, but we have a weakness when it comes to applying and respecting our laws. About 90% of the government employess are not aware of the laws for disabled. we face a lot of problem with government functionaries.

Henant Tandi, OH, Elected Representative Panchayat, Nabrangpur

I just wanted to die after I had my amputation. For many years I suffered humiliation and discrimination because neither I nor my family, nor any of the government or political persons in Kharihar were aware of the laws for disabled people.

Pradip Aggarwal, OH, Disability Activist, Nuapada



As the disability certificate is the basic document for PWDs to avail any benefit, State Governments must organize special campaigns in the areas where large number of persons with disabilities are yet to be issued disability certificates.

*Mukul Wasnik
Hon'ble Minister, SJ&E, GoI
(National Conference of State
Commissioners) , New Delhi, 2011*



2.6 Government Entitlements

PWD are entitled to benefits and supports specifically related to their disability. These supports serve a range of purposes – some aim to provide mobility and communication, some income generation and some give social security. Evidence suggests awareness of government entitlements and availing are low, and lower among households with PWD than others. While awareness of specific entitlements is higher, it remains low for most benefits. Despite being ground-breaking in recognizing the multi-faceted nature of disability PWD Act 1995 covers only designated types of disability, which are not inclusive of several significant categories of disability (e.g. autism). This is in part driven by the linkage between the legal definition of disability and entitlements. Second, entitlements are often legally framed in a general manner which does not facilitate enforcement, and/or not linked to any sanctions for non-compliance.

Compensatory benefits were the first to be introduced in UK. The War Disability Pension, created after the First World War, was one of the earliest social security benefits altogether. Industrial Injuries Disablement Benefit followed in 1948 (Berthoud, 1998). Research has been done to examine the practical operations of claiming and assessing benefit (Sainsbury et al., 1995, Hawkins et al., 2007). It is obvious that disabled people are better off with their benefit than without it, and some surveys have recorded their reaction of happiness when they start to receive it (e.g. Craig et al., 2003).

Entitlements find reflection in the Constitution of India in its chapter on 'Directive Principles of State Policy.' It declares that it is the duty of the State to secure a social order in promotion of the welfare of the people in which justice, social, economic and political shall inform all the institutions of national life. The State policy has to be directed to secure that the citizens, men and women, equally have the right to an adequate means of livelihood, the economic system is operative for the common good, there is equal pay for equal work for both men and women, that citizens are not forced by economic necessities to enter avocations unsuited to their age and strength. The State shall make provisions for securing the right to work to education and public assistance in case of unemployment, old age, sickness and disablement and in other cases of undeserved want. The State also has the responsibility of promoting with special care the educational and economic interests of the weaker sections of the people particularly the scheduled castes and scheduled tribes and protect them from all sorts of social injustice.

PWD Act 1995 has been a landmark legislation and is an official instrument for equal opportunities in its true sense. It addresses entitlements in almost every sphere of a PWDs life, education, employment, transport, access, social security etc (Box-9).

Box 9**World Bank Report (2004)**

Broadly, the entitlements and commitments towards PWD under the Act can be divided into two main groups: (i) entitlements which are absolute and thus in nature of legal rights. Some of these existed as rights prior to the Act but were reiterated or strengthened in the Act itself (and have in some cases been refined subsequently); and (ii) commitments that are given either in rather general terms or with the explicit proviso “within the limits of [governments’] economic capacity and development”. These can be described as “contingent entitlements” under the Act and are not unqualified rights. The division is not entirely clearcut, as subsequent jurisprudence has in some cases strengthened general commitments.¹⁷⁸ In a number of cases, follow-up action is also anticipated by states or other relevant authorities.

UNCRPD has opened the doors wide for entitlements by the very first Article (1) - The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. In Article 2 it defines reasonable accommodation which paves way for entitlements in all spheres of life. Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

2.6.1 Disability Certificate

Disability evaluation is needed to award compensation, stipends, employment, conveyance allowance, travel concessions, tax-deduction benefits, admission to various courses etc. to the disabled. Disability certificate is not just a document for a person with disability but a proof of his/her disability and an important tool for availing the benefits / facilities/rights that they are entitled to, from the Central as well as State Government under various appropriate enabling legislations. The Ministry of Social Justice & Empowerment has notified procedures for the medical boards of district civil hospitals for issuance, assessments and the format of disability certificate. However there are many lacunae (Box-10).

Box 10**Lacunae in the present methods of disability evaluation***

1. *Disability is not purely a medical condition. It involves physical, social and psychological impairments. At present evaluation of disability is done by the medical doctor who is specialized to evaluate only the medical aspect of disability i.e. physical impairment.*
2. *Social and psychological activities/potential are never considered while giving the disability assessment certificates. Hence the present system of issuing disability evaluation certificate is defective.*
3. *A paraplegic person may be totally permanently physically impaired, but if he has potential to earn his living, his disability can't be labeled as total. But with present system of evaluation no such demarcation has been made between disability and physical impairment. This is one of the greatest lacunae in the present system of disability evaluation.*
4. *Autistic persons are always being evaluated as mentally retarded. An autistic person is anything but mentally challenged.*
5. *In most of the medical boards percentage of disability is being accorded as per the whims of the doctors. No proper evaluation is being done.*

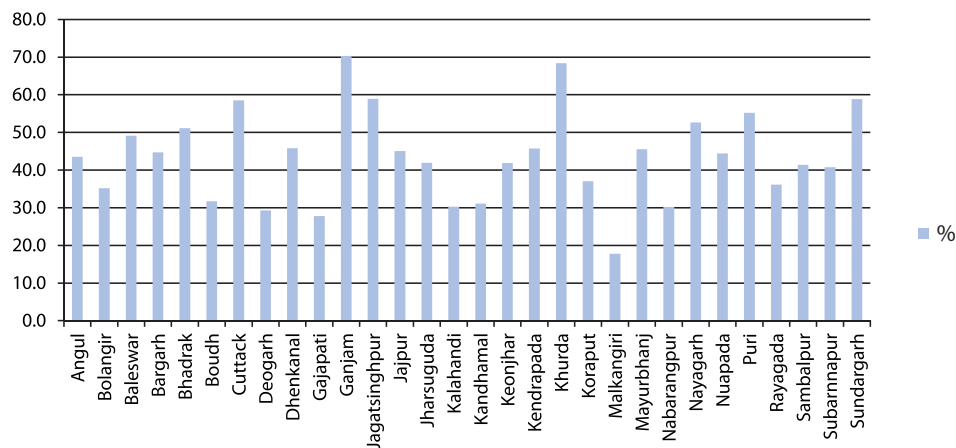
* Inputs from state consultation held on 21/03/2012 at Bhubaneswar

Only 48.8% of PWDs possess a disability certificate. Ganjam tops the list with 70.5% (Box-11) and is followed by Khurda (68.4%), Jagatsinghpur (58.9%), Sundergarh (58.8%) and Cuttack (58.5%). Malkangiri languishes at the bottom with 17.8% (Table-29 and Graph-15). With respect to certification, the standard model is to rely on assessment and certification by teams at district hospitals. The obvious shortcoming of the system is that rural populations often have low knowledge of and access to such teams (in addition to the costs associated with accessing district headquarters). In addition, evidence from our 2004 study indicates that arrangements for disability certification do not always function well, with only just over 10% percent of hospitals having disability certification schedules in place. 7 years later though the hospitals have a schedule, they do not adhere to it.

During interview with Mr. R.K.Sharma, Rehabilitation Officer of VRC Bhubaneswar, he elaborated on the following four points : a) Certification of 4 categories of PWD mentioned in National Trust Act- 1995 (Autism, CP, MR & MD) needs to be strengthened, b) Uniformity should be brought in forms, formats, and register with coding system to keep track of certificates issued, c) There are cases where disability is permanent but temporary disability certificate is/are issued, which is violation of existing rules, and d) Severely disabled persons, particularly poor children with disabilities, women with disabilities, specially in rural and remote areas, should be brought by Government transport to nearest disability certificate place because majority of them are left out.

Table 29 : Possession of disability certificates (District wise)

Sl. No.	District	Number	%
1.	Angul	54	43.5
2.	Bolangir	45	35.2
3.	Baleswar	108	49.1
4.	Bargarh	76	44.7
5.	Bhadrak	91	51.1
6.	Boudh	13	31.7
7.	Cuttack	155	58.5
8.	Deogarh	12	29.3
9.	Dhenkanal	55	45.8
10.	Gajapati	15	27.8
11.	Ganjam	265	70.3
12.	Jagatsinghpur	66	58.9
13.	Jajpur	95	45.0
14.	Jharsuguda	26	41.9
15.	Kalahandi	40	30.3
16.	Kandhamal	23	31.1
17.	Keonjhar	59	41.8
18.	Kendrapada	70	45.8
19.	Khurda	173	68.4
20.	Koraput	40	37.0
21.	Malkangiri	8	17.8
22.	Mayurbhanj	102	45.5
23.	Nabarangpur	35	30.2
24.	Nayagarh	50	52.6
25.	Nuapada	24	44.4
26.	Puri	128	55.2
27.	Rayagada	30	36.1
28.	Sambalpur	48	41.4
29.	Subarnapur	22	40.7
30.	Sundargarh	100	58.8
	Total	2028	48.8



Graph 15 : Possession of disability certificates

Box 11

Progressive district Ganjam



The reason for non-possession of disability certificate varied from lack of awareness, which included lack of information about existence of the certificate and the place where it was issued (43.4%), 16.1% stated the difficulties faced in medical boards as a demotivating factor, 24.6% felt medical board was at a very distant place and 6.5% found bribing a difficult barrier to cross and 9.3% gave a combination of reasons like no one to accompany, no one to offer a ride, family members ignored the issue, lack of evaluation of deafness, autism, multiple disabilities etc (Table-30).

Table 30 : Reasons for non-possession of disability certificates		
Causes of not having disability certificate	Number	%
I don't know	1017	43.4
Difficulty faced in medical board	377	16.1
Difficult to go to the district head quarter hospital	577	24.6
Commission and bribe	152	6.5
None of these	218	9.3
Total	2341	100

2.6.2 Disability Pension

In Andhra Pradesh pension amount is Rs.500 per month, in Goa 750, in TN 1000, Chandigarh 400 etc but Odisha has a measly Rs. 300 per month. In February 2009, IGNWPS was started to provide pension of Rs 200 per month per beneficiary to BPL widows in the age group of 40–64 years and IGNDPS was also started in the same month for BPL persons with severe or multiple disabilities (in the age group of 18–64 years) at the rate of Rs 200 per month per beneficiary. Odisha is yet to take benefits from both.

On an average only 17.4% of PWD get disability pension in Odisha (Table-31). More work is needed to understand the constraints in accessing disability pension. The main deterrent to applying for DP among those potentially eligible for disability pension is 'process too complicated', which put off about half of potential applicants among our respondents, with almost a further 10% citing 'don't know how' as the reason for not applying. The other aspect is a degree of fiscal rationing in aggregate numbers of disability pensioners as the schemes are state-funded entirely. There has been introduction of a centrally sponsored scheme 'Indira Gandhi National Disability Pension Scheme' which aims to provide pension to 'severely disabled persons.'

Table 31 : Recipients of disability pension

Sl. No.	District	Number	%
1.	Angul	21	16.9
2.	Bolangir	20	15.6
3.	Baleswar	38	17.3
4.	Bargarh	26	15.3
5.	Bhadrak	32	18
6.	Boudh	5	12.2
7.	Cuttack	59	22.3
8.	Deogarh	6	14.6
9.	Dhenkanal	23	19.2
10.	Gajapati	7	13
11.	Ganjam	92	24.4
12.	Jagatsinghpur	21	18.8
13.	Jajpur	30	14.2
14.	Jharsuguda	8	12.9
15.	Kalahandi	15	11.4
16.	Kandhamal	10	13.5
17.	Keonjhar	20	14.2
18.	Kendrapada	30	19.6
19.	Khurda	57	22.5
20.	Koraput	16	14.8
21.	Malkangiri	2	4.4
22.	Mayurbhanj	31	13.8
23.	Nabarangpur	12	10.3
24.	Nayagarh	14	14.7
25.	Nuapada	8	14.8
26.	Puri	52	22.4
27.	Rayagada	11	13.3
28.	Sambalpur	19	16.4
29.	Subarnapur	7	13
30.	Sundargarh	31	18.2
	Total	723	17.4

2.6.3 Aids and Appliances

Bhagwan Mahaveer Viklang Sahayata Samiti (BMVSS) Jaipur, provides artificial limbs, callipers, crutches, ambulatory aids like wheelchairs, hand paddled tricycles and other aids and appliances in Odisha. ALIMCO, an ISO 9001-2000 company, is the premier and the largest manufacturer of quality aids and appliances in whole of South Asia. It also supplies aids and appliances. Government of Odisha provides all the artificial limbs, calipers, crutches, ambulatory aids like wheel chairs, hand paddled tricycles and other aids and appliances free of charge to those PWD who cannot afford them. However, most young PWD (state consultation 21 March 2012) resent the quality and type of aids and appliances distributed by government.

Though 34.4% are aware of the free distribution of aids and appliances (Table-32) yet only 18.6% are recipients (Graph-16). Three main challenges in receiving benefits and services include: (i) physical access problems; (ii) problems with procedures and officials; and (iii) communication difficulties for disabled people in approaching providers. Since mobility of the PWD is one of the major constraints associated with disability, the provision of requisite aids and appliances carries greater significance for the PWD. In view of this, only 18.6% people were found to be having requisite aids and appliances with them. 81.4% did not have the aids and appliances which in addition to their disability pose a major challenge for them to become mobile and functional (Table-33). This is one of the important findings that the state needs to look in for initiating action to functionalize the PWD so that they can be able to do perform to their optimum.

Table 32 : Awareness of aids and appliances free distribution

Awareness of free distribution	Number	%
Yes	1385	34.4
No	2003	49.7
May Be	641	15.9
Total	4029	100

Table 33 : Recipients of aids and appliances

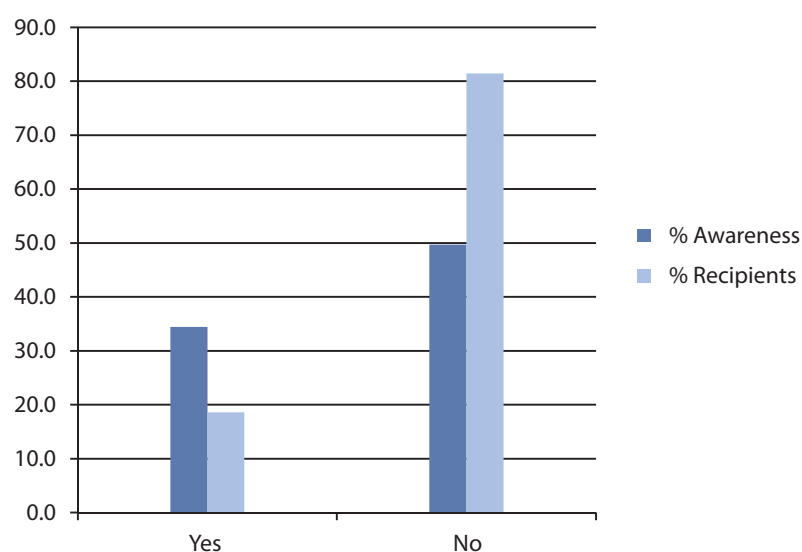
Responses	Number	%
Yes	592	18.6
No	2593	81.4
Total	3185	100

Table 34 : Common aids and appliances distributed

Common aids and appliances	Number	%
Wheel Chair	96	23.7
Tricycle	130	32.1
Cane	31	7.7
Crutch	13	3.2
Hearing Aid	92	22.7
Tape Recorder	10	2.5
Other*	33	8.1
Total	405	100

* Lower lean orthotic (calipers), lower lean prosthetic (artificial leg), upper lean prosthetic (artificial hands), socks and surgical boots

The obsolete aids and appliances distributed (Table-34) must be removed from government's list and newer ones added (state consultation input November 2012). Tape recorder should be replaced by digital voice recorders or mobile phones with 4GB storage. Mobility aids are heavy and not durable. Moreover there is no local assembling, repair, and maintenance facility for most mobility aids and appliances.



Graph 16 : Comparative figures of PWD aware and the recipients of aids and appliances

Box 12**Observation report of medical boards and Bhima Bhoi scheme by research team**

1. *Unavailability of adequate experts. For ex. In Kandhamal and Jagatsinghpur, there are no experts for HI and MR, so the PWD travel to Berhampore Medical College after being referred from their CDMO.*
2. *Distance of the medical board from the rural pockets is also a problem. For ex. In Bolngir, Nuapada and Koraput PWD complain of the long distances they have to travel.*
3. *Doctors treated PWD rudely (Capital Hospital, Bhubaneswar and SCB Medical College, Cuttack)*
4. *Doctors asked for referral to medical colleges (Puri, Balasore, Bhadrak, Nuapada, Sundergarh)*
5. *During Bhima Bhoi Samarthya Sibir a lot of fake medical certificates are being distributed (ex. Kalahandi – activists discovered a 20% forgery in certificates). This is because of an absence of record keeping and lack of computerization.*
6. *In Ganjam fake certificates are a big issue and non-disabled persons pay huge bribes to get disability certificates to avail government benefits.*
7. *From Sundergarh ASHA Karmis described their woe that many a times they bring the same person twice or three times, to increase their percentage, because they have to show the 'numbers' to their higher authorities. Pressure of numbers was also felt by AWW, VLW etc.*
8. *PWD from all 30 districts opined that ASHA are not taking their task seriously as there are .*
9. *Time and venue notification of Bhima Bhoi Samarthya Sibir is not being done properly. So many PWD are unable to attend.*
10. *As it is an integrated empowerment camp the success of this camp depends on various office and institutions but a complete lack of coordination is always visible. Some always remain absent like doctors, bank official, transport official and rehabilitation professionals. In many occasions officials come to the camp without forms for bus and train concessions.*

Recommendations

1. Putting the onus of certifying disability on the state as is the case in issuing of a passport, which is delivered at the doorstep once the application has been filed.
2. PWD to appear before one doctor specialising in the nature of disability instead of a Medical Board which is a time consuming process as doctors often skip board meeting.
3. Empowering the doctors at the PHC level to issue disability certificates of all categories of disability to reduce the stress of long distance travel.
4. Provision of waiting room, toilets, signages and information in alternate format in hospitals for PWD.
5. Committee to be set up to review the aids and appliances to be distributed. More number of educational aids which are relevant to be provided. For ex. Instead of tape recorders, digital voice recorders or mobile phones with 8 GB memory will be better aids in capturing class room lectures.
6. Some suggested aids and appliances are decoders for television sets in order to enable access to captions on television, head pointers, buzzers, adapted keyboards, advance screen reading software, daisy recorders, Braille displays and Braille note. This should be in addition to wheel-chairs, tricycles, hearing aid, artificial limbs and canes.
7. All government suppliers of aids and appliances to have certification of quality; and are to make provisions for repairs and after sales service.
8. List of officials in every panchayat and municipal area to be authorised to issue disability.

Voices

Government of India is not giving funds to NIRTAR and ALIMCO under ADIP Scheme. These organizations have a strong base and wide reach across the state. Instead the money goes to Naryan Seva Sanstha and Mahavir Vikalanga Seva Sanshtan based in Rajasthan which have no infrastructure in Odisha. Hence aids and appliances are not reaching PWDs.

P.R.Das, Ex Head of ALIMCO, Bhubaneswar

Disability Certificate is like a passport for Persons with Disabilities which makes them enable to avail the benefits, concessions for them. Government of Odisha. There are shortage of medical expert particularly Psychiatric, audiologist, psychologists etc therefore Odisha PWDs rules 2003 need to be amended in light of the Government of India PWD rules. Uniformity should be brought in forms, formats, and register with coding system keep track”

R.K.Sharma, Rehabilitation Officer, VRC, Bhubaneswar



Globally it is estimated that 70 per cent of children with disabilities, including those with mild mental retardation, can attend regular schools provided the environment is designed to be accessible and the institution is willing to accommodate them.

*Cecilia Lotse
UNICEF Regional Director for South
Asia (UNICEF Consolidated Report)*



2.7 Education

While the 650 million people worldwide who live with a physical, sensory (blindness, deafness), intellectual or mental health disability make up 10% of the world's population, according to the World Bank, they make up 20% - or one out of every five of the world's poor. (Elwan, 1999) In the early 1990s, UNESCO estimated that perhaps 97% of these people had either never seen the inside of a classroom or had left school too early to have mastered basic literacy and numeracy skills resulting in literacy rates for adults with disabilities in developing countries possibly as low as 3% overall, and for women with disabilities, 1%. (Helander, 1993). These statistics became an area of significant concern and helped lead to the 1994 Salamanca Statement and Framework for Action on Special Needs Education. The Salamanca Statement, building on the right to education for all guaranteed in the UN Convention on the Rights of the Child, stated: "(we) hereby reaffirm our commitment to Education for All, recognizing the necessity and urgency of providing education for children, youth and adults with special educational needs..." (UNESCO, 1994).

The PWD Act has articulated the chapter on education eloquently (Box-13).

Box 13

Chapter V - Education (PWD Act, 1995)

26. *The appropriate Governments and the local authorities shall-*
 - a. *Ensure that every child with a disability has access to free education in an appropriate environment till he attains the age of eighteen years;*
 - b. *Endeavor to promote the integration of students with disabilities in the normal schools;*
 - c. *Promote setting up of special schools in Government and private sector for those in need of special education, in such a manner that children with disabilities living in any part of the country have access to such schools;*
 - d. *Endeavor to equip the special schools for children with disabilities with vocational training facilities.*
27. *The appropriate Governments and the local authorities shall by notification make schemes for-*
 - a. *Conducting part-time classes in respect of children with disabilities who having completed education up to class fifth and could not continue their studies on a whole-time basis;*
 - b. *Conducting special part-time classes for providing functional literacy for children in the age group of sixteen and above;*

30. *Without prejudice to the foregoing provisions, (be appropriate Governments shall by notification prepare a comprehensive education scheme which shall make Provision for-*
 - a. *Transport facilities to the children with disabilities or in the alternative financial incentives to parents or guardians to enable their children with disabilities to attend schools.*
 - b. *The removal of architectural barriers from schools. colleges or other institution, imparting vocational and professional training;*
 - c. *The supply of books, uniforms and other materials to children with disabilities attending school.*
 - d. *The grant of scholarship to students with disabilities..*
 - e. *Setting up of appropriate fora for the redressal of grievances of parent, regarding the placement of their children with disabilities;*
 - f. *Suitable modification in the examination system to eliminate purely mathematical questions for the benefit of blind students and students with low vision;*
 - g. *Restructuring of curriculum for the benefit of children with disabilities;*
 - h. *Restructuring the curriculum for benefit of students with hearing impairment to facilitate them to take only one language as part of their curriculum.*
31. *All educational institutions shall provide or cause to be provided amanuensis to blind students and students with or low vision.*

The right to education is strongly supported in the newly ratified Convention on the Rights of Persons with Disabilities (UN, 2006) where Article 24 states that 'States Parties shall ensure an inclusive education system at all levels and lifelong learning... 'Although the right to education is primarily framed as a school-based issue for children, certain articles of the Convention are linked to adult literacy. Article 24 itself refers to 'youth and adults', and Article 21 re-affirms the freedom of expression, opinion, and access to information, while Article 29 refers to the right to participation in political and public life. (UN Declaration 2006) The ability to exercise these rights is directly related to the mastery of literacy skills.

Despite the Gol declaration that 'It should, and will be our objective, to make mainstream education not just available but accessible, affordable and appropriate for students with disabilities,' accessing education is one of the greatest necessity and also one of the greatest challenge for PWD. Though colleges and universities follow the 3% reservation policy regarding the admission of SWD, none of them have any policy concerning the infrastructure and other facilities required by SWD in the college premises.

According to 2011 census Odisha has a literacy rate of 73.5%. Unfortunately literacy rate of persons with disability is at a dismal low with only 57.8%. While 42.2% have no formal education, only 30.1% have passed primary school. 14.2% are class 8th pass, 8.9% are matriculate and 3.3% are graduates. 0.9% have a post graduate degree and 0.4% are technical degree holders (Table - 35).

Table 35 : Literacy rate		
Educational Level	Number	%
No formal education	1752	42.2
Primary school	1249	30.1
Class 8th pass	587	14.2
Matriculate	368	8.9
Graduate	138	3.3
Post graduate	39	0.9
Technical	19	0.5
Total	4152	100

2.7.1 Primary Education

In keeping with the spirit of the Article 21A of the Constitution guaranteeing education as a fundamental right and Section 26 of the Persons with Disabilities Act, 1995, government is committed to providing free and compulsory education to all children with disabilities up to the minimum age of 18 years. The National Policy on Education (NPE), 1986 and the Program of Action (1992) gives the basic policy framework for education, emphasizing the correcting of existing inequalities. It stresses on reducing dropout rates, improving learning achievements and expanding access to students who have not had an easy opportunity to be a part of the mainstream system. The 93rd Amendment of the Constitution of India has made education a fundamental human right for children in the 6-14 years age group thereby making it mandatory for all children to be brought under the fold of education. This includes children with disability.

UNCRPD devotes Article 1-4 in ensuring educational facilities for all persons with disabilities in an inclusive setting. Our country at present is pursuing the same approach of encouraging integrated and inclusive education wherever possible and retaining residential institutions for the children who need the same due to nature of their disability and such other factors. Various initiatives taken in India during the recent years establish that our efforts are very much in consonance with the principles, policy as well as priority areas enunciated in the United Nations Education for All initiative, first launched at Jomtien, Thailand in 1990 and re-affirmed

and strengthened by the Salamanca Statement (1994) and Dakar Declaration and Framework for Action (UNESCO 2000), by the UN Standard Rules (Rule 6) on the Equalization of Opportunities for Persons with Disabilities (United Nations 1993), ESCAP Biwako Millennium Framework (2002), and UNCRPD (2007).

These initiatives include:

- Evolving and implementing Scheme of Integrated Education of Children with Disabilities during 1974.
- The National Policy on Education (NPE), 1986 and the Program of Action (1992)
- RCI and NIMH Mandate
- UNICEF sponsored Project on Integrated Education of Disabled Children, 1990.
- District Primary Education Program, 1995.
- Persons with Disabilities Act, 1995.
- Scheme of Assistance to Non- Governmental Organizations for Persons with Disabilities.
- National Program on Rehabilitation of Persons with Disabilities.
- The National Curriculum Framework for School Education (NCERT, 2000).
- Sarva Shiksha Abhiyan, 2000
- The Right to Free and Compulsory Education Act 2009

OPEPA through SSA program is working towards inclusion of CWSN in education program. As per annual reports of OPEPA out of school children and drop out rates are both decreasing for CWSN. Infrastructure is being made friendly and corrective surgeries are being done along with provision of aids and appliances. In 2010-11, 3690 were provided aids and appliances (Table-37) and 125980 CWSN were enrolled (Table-36), 388 number of CWSN were provided with surgical correction (Table-38) in cleft palate, cleft lip, cataract, orthopedic surgery and ear drum surgery.

Table 36 : Identification and enrollment of CWSN in SSA Schools*

Year	Identified	Enrolled
2008-09	126245	115344
2009-10	124741	116801
2010-11	123101	115538
2011-12	123939	125980

* Source : OPEPA Annual Report 2012

Table 37 : Details of infrastructure modification and provision of aids and appliances*

Year	No. of ramps constructed in schools	No. of toilet made barrier free	No. of aids & appliances provided to CWSN
2008-09	7755		14578
2009-10	6526		18352
2010-11	10901	3656	11583
2011-12	580	320	3690

* Source : OPEPA Annual Report 2012

Table 38 : Corrective surgeries report*

Year	Number
2008-09	788
2009-10	1003
2010-11	1273
2011-12	388

* Source : OPEPA Annual Report 2012

Despite all this CWSN in Odisha are yet to be fully integrated into the school culture. Our study includes children and teachers both from SSA and special schools. Most of the CWSN remain out of school but the few who go enjoy school. 82% enjoy going to school. 54% said they had resource teachers, 11% said their schools had resource rooms, 28% participate in sports, 35% could access toilets and 18% are getting some form of scholarship (Table-39).

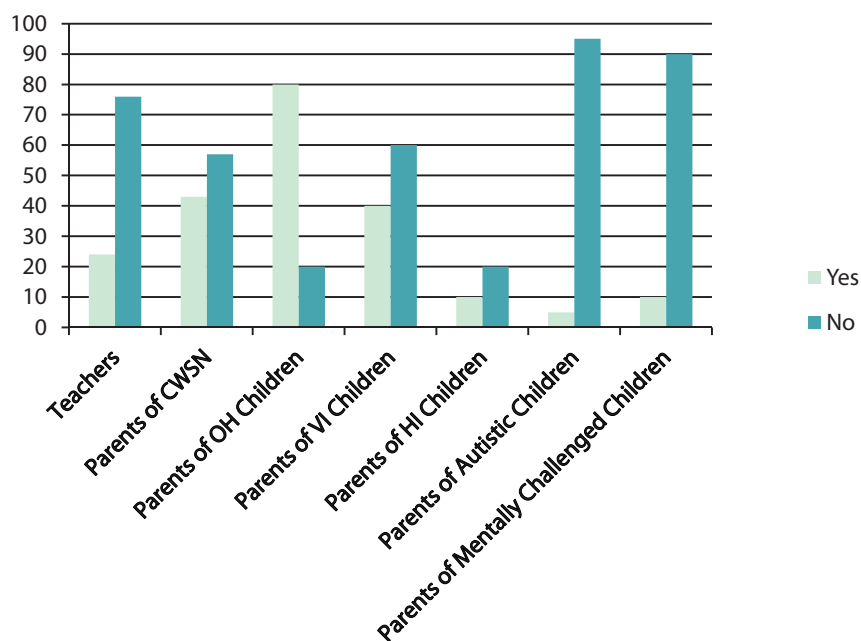
Table 39 : Response of school going CWSN (in %)

Responses	Yes	No
Do you enjoy school?	82	28
Are there special teachers to take care of you?	54	46
Do you have a resource room in school?	11	89
Do you have learning teaching aids?	35	65
Do you participate in sports and cultural events?	28	72
Are you able to access a toilet?	35	65
Do you get any scholarship for studying in school?	18	82

Our interview of teachers found that 100% of them enjoy teaching but 92% expressed fatigue being overburdened. 89% said they have received training but only 12% expressed satisfaction with the training. They felt it was short and there was no clarification of their doubts and questions. 65% of the teacher respondents were satisfied with the learning teaching aids. 18.9% confirmed that their schools have resource rooms for CWSN. 38% consented that they have adequate knowledge of assistive and adaptive equipments. 21.6% expressed their having adequate knowledge about the environmental adaptations needed by students with physical disabilities. 24% of teachers have adequate knowledge about the disabilities specific characteristics and health care needs of students with physical disabilities (Table-40).

Table 40 : Response of school teachers (%)		
Responses	Yes	No
Do you enjoy teaching?	100	0
Have you received any training?	89.2	10.8
Were you satisfied with the training ?	12	88
Do you have good learning teaching aids in school?	64.9	35.1
Do you have resource room in your school for CWSN?	18.9	81.1
Are you overburdened	92	8
Do you feel competent and adequately prepared for the inclusion of students with physical disabilities in their classrooms ?	40.5	59.5
Do you have adequate knowledge about assistive and adaptive equipment?	37.8	62.2
Do you have adequate knowledge about the environmental adaptations needed by students with physical disabilities?	21.6	78.4
Do you have adequate knowledge about the disabilities specific characteristics and health care needs of students with physical disabilities?	24.3	75.7
Do you have adequate knowledge about the social needs of students who have physical disabilities?	51.4	48.6
On the avrage how many clock hours of in-service training have you received to integrate students with physical disabilities in the classrooms?	27	73
Should CWSN go to mainstream schools ?	24	76

Most teachers and parents were of the opinion that the CWSN should go to special school (Graph-17). The anxieties expressed by parents included among others, the lack of awareness of the school authorities on the issue. Other concerns were schools do not have the required infrastructure-like ramps, restrooms with proper facilities required by CWSN, teachers are not equipped with the necessary skills to handle CWSN, teachers advise them to admit their children to 'special schools', and some schools even go to the extent of asking for extra money for the special care that these children would need. Also, even though some schools do take in these children, they never try to accommodate him/her and make no provisions for revising the curriculum, restructuring the examination system or training teachers to properly implement this 'inclusion' in practice. In addition to this, there is a lot of negative attitude of the parents of the other students regarding the admission of children with disabilities. CWSN often become victims of petty cruelties of people.



Graph 17 : Response of teachers and parents on inclusive education

2.7.2 Higher Education

When universities did not respond to our research team nor acknowledge our letters, eleven universities in Odisha were asked for information through RTI. A total of eight universities responded. There was no response from any BPUT and Ravenshaw, two of the important and premier institutions. Ravenshaw is the oldest college (now university) and the

present day who's who of the state hail from here. It is unfortunate that this heritage university remains silent on higher education for students. No university has any special schemes for its students with disabilities. This is almost the same as the national scenario (NCPEDP 2004). Excerpt from a research by NCPEDP (2004) - *"According to the University Grants Commission (UGC), 6% of India's youth population is in Universities and Colleges. Proportionately, based on the most conservative estimate for the disabled youth population in the country (National Sample Survey, 2003), at least 3160,000 disabled youth should be in the Universities and Colleges of India. However, just 1.2% of the 3.6 lakh disabled youth, who should have been studying according to India's norm for the general youth population, are in the Universities and Colleges. It brings the stark reality into an established truth that India's higher educational system is not accessible to 98.8% of its disabled youth."*

Responses from Odisha Universities (RTI Filed by ex. staff of Swabhiman in 2009) reflects a grim situation for students with disabilities in higher education. The number is very small and there are no special facilities available (Table-41).

Table 41 : Number of students with disabilities in University*	
Name of the University	Students with disabilities admitted since 1996
OUAT, Bhubaneswar	2009-10 : 24 in BA and 5 in MA and 1 in +3 Science
Fakir Mohan University, Baleswar	2009-10 - 12 students 2004-05 - 3 students 2005-06 - 3 students 2008-09 - 4 students 2009-10 - 2 students
Sambalpur University, Burla	28 after 1996
North Orissa University, Baripada	2 students
Berhampur University, Gopalpur	63 Students
Utkal University, Bhubaneswar	27 in MA and 27 in M Phil

* Response to RTI application filed by Sagarika Subhadarshini, ex. staff of Swabhiman (2009)

To the question 'what are the facilities being provided and what are the schemes implemented by the University for students with disabilities', all universities answered in negative. Same was the response to what are the special facilities available in your

university hostel for the SWD. The responses to 'do students with disabilities participate in sports and extra curricular activities' reflected the grim apathetic situation in PWDs live in our society. Sambalpur and Berhampur Universities explained non-participation as the reason behind non availability of special provisions for students with disabilities where as North Orissa University went a step ahead and remarked that SWD have no interest in sports (Table-42).

Table 42 : Participation of SWD in sports*

Sambalpur University, Burla	Students are not taking part in sports so there is no for provision them to take part in the inter college tournament
North Orissa University, Baripada	They are not interested
Berhampur University, Gopalpur	They do not participate
Sambalpur University, Burla	No specific provisions for them
Utkal University, Bhubaneswar	No response

* Response to RTI application filed by Sagarika Subhadarshini, ex. staff of Swabhimani (2009)

To the question 'what are the special facilities has been for students with disabilities in library, laboratory & auditorium', only Utkal University responded with railings and ramp, 3 computers with jaws soft ware in psychology department; and braille embosser for print out and study material.

UGC had started the scheme of assistance to universities to facilitate teacher preparation in special education and support students with special needs during the Ninth Five-Year Plan, which continued in the Tenth Plan and now continues, keeping in view the need to provide special education programs as well as infrastructure to differently-abled persons. In the Eleventh Plan this continues. SWD require special aids and appliances for their daily functioning. These aids are available through various schemes of the Ministry of Social Justice and Empowerment. In addition to the procurement of assistive devices through these schemes, the higher education institution may also need special learning and assessment devices to help differently-abled students enrolled for higher education. Availability of devices such as computers with screen reading software, low-vision aids, scanners, mobility devices, etc., in the institutions enrich the educational experiences of

SWD. Therefore, universities are encouraged to procure such devices. The UGC will provide an ad hoc one-time grant of up to Rs. 8.0 lakhs per university/college during the Eleventh Plan period. An RTI application filed by Sruti Mohapatra of Swabhimani (2012) shows that none of the institutions in Odisha are taking benefits of that (Table-43). This is a reflection of an unhealthy society which has not much concern for its underprivileged members.

Table 43 : Response to HEPSN & TEPSE*

SL.No	Name of the University	Responses of the Universities
1	Berhampur University	No Visually challenged permanent teacher is working in this University.
2	Biju Pattnaik University of Technology, Odisha, Rourkela	<ol style="list-style-type: none"> 1. The University has not been declared fit under 12 B of UGC Act. Hence no grant has been received in any form from the UGC including TEPSE/HEPSN schemes till 2011-12. 2. The University has no information about HEPSN scheme of UGC. 3. No Visually challenged permanent teachers have been employed in this University. However the University allowing extra-time during conduct of examinations to physically challenged students pursuing study at different affiliated colleges.
3	National Institute of Technology Rourkela	<ol style="list-style-type: none"> 1. NITR is not under administrative control of the UGC & accordingly has not received any fund from UGC under the TEPSE in any year. 2. There is no visually challenged faculty in NIT Rourkela. 3. NIT provides equal opportunity to the physically challenged students and employees.
4	North Orissa University Sriram Chandra Vihar, Takatpur, Baripada	<ol style="list-style-type: none"> 1. The University requested the construction agencies to provide access facilities to differently abled persons.

		2. Amount spent in procuring special learning and assessment devices in 2010-11 to help differently abled students enrolled for higher education may be obtained from Store/Library of NOU.
5	KIIT University, Bhubaneswar- 24	<p>1. KIIT University has not received any grant from UGC under TEPSE scheme.</p> <p>2. KIIT University has not received any grant from UGC under HEPSN scheme.</p> <p>3. The University has ramp and lift facilities in all campuses to make the campuses barrier free and accessible to all.</p> <p>4. KIIT University has not received any application from visually challenged persons for teaching/ research position of the university. On receipt of such application, the university will take steps to provide all types of necessary teaching/ research facility for visually challenged persons.</p>
6	Siksha 'O' Anusandhan University Bhubaneswar	<p>1. No grant received under HEPSN and TEPSE.</p> <p>2. No UGC Scheme operating</p> <p>3. 3% reservation provided for physically disability candidates for admission operational.</p> <p>4. Ramps provided in institute buildings.</p> <p>5. We do not have any visually challenged teachers.</p>
7.	Sri Sri University, Bhubaneswar	<p>1. We have not applied nor sought any grant from UGC scheme till date.</p> <p>2. Though this University has not taken any grant nor benefited from the schemes, as a responsible University managed by an NGO we have taken necessary measures in building the campuses barrier free.</p>

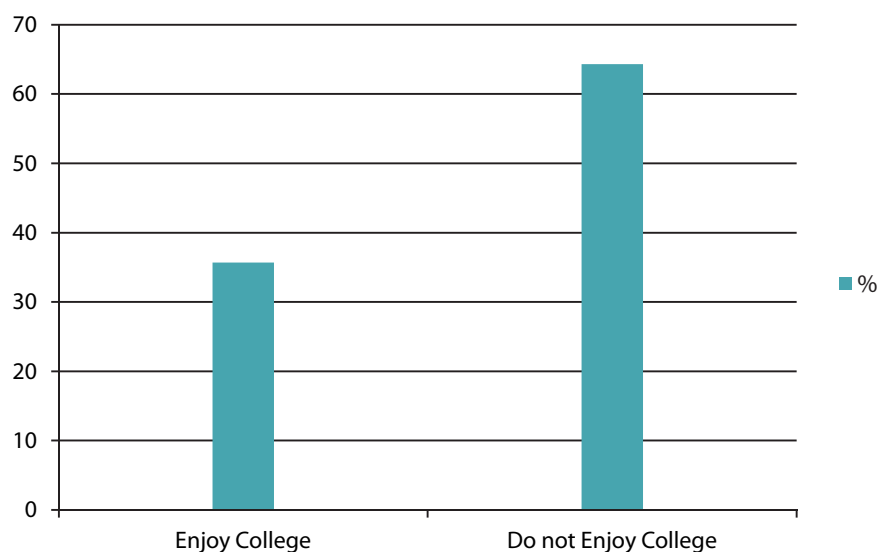
		<p>3. Since this University is under conceptual stage, our focus on learning will be from academic year 2012 onwards.</p> <p>4. As stated above so far as we have not derived any schemes but we will conceptualized and provide enough opportunities for visually challenged permanent teachers to pursue teaching & research.</p>
8	Veer Surendra Sai University of Technology, Odisha, Burla	<p>1. No grant/fund has been received at this end from UGC.</p> <p>2. Since 2008-09 till date on account of schemes TEPSE & HEPSN. Hence there is no expenditure.</p> <p>3. There are no visually challenged permanent teachers available in the University.</p>
9	Centurion University of Technology and Management Bhubaneswar	<p>1. Centurion University received no such grant from UGC.</p> <p>2. Centurion University has alternate access in all the buildings.</p> <p>3. We do not have any visually challenged teachers.</p>
10	Utkal University Vani Vihar, BBSR-751004	<p>1. Rs.8,78,000,00 in 2008-09.</p> <p>2. Two rooms with one attached toilet is being used to run the HEPSN program in the dept of Psychology. Named Samarthya, it houses the 3 computer systems for enabling the students with visual impairment.</p> <p>3. Ramps with side support railings have been constructed to provide access to the Library, Hospital, University office and the departments.</p>

		4. No person with visual impairment has so far been employed by the university. We have plans to make the computer centre disabled friendly and to provide the support as and when necessary.
11	Sambalpur University Burla, Sambalpur	PG.Council Office has not received any grant under TEPSE or HEPSN UGC scheme during the year 2008-09, 2009-10 & 2010-11.

* Response to RTI application filed by Sruti Mohapatra, Swabhimani (2012)

Joy of Learning

The total number of students in our respondent group were 585. As against 35.7% who enjoy going to college 64.3% do not enjoy their college days (Graph-18). During the focus group discussions (Box-13 and 14) the various reasons came to the fore. Basic requirements are not being met. It was found that none of the colleges in the state provide simple basic needs like a disabled-friendly toilet or an accessible drinking water tap. This is in clear violation of PWD Act 1995. While University Grants Commission, the nodal authority, has schemes for providing funds and equipment to make colleges barrier-free, the deans of the colleges were found to know little about them.



Graph 18 : Joy of learning

Box 14**FGD at Utkal University, Bhubaneswar (VI Students)**

1. *Lack of text books in braille or audio books.*
2. *Lack of hostel facilities for students who get admission. Daily travel to college/university is very problematic as private buses do not respect the disability concessions to be provided.*
3. *Exemption of admission and examination fee, as introduced by higher education department, is not being universally implemented across all the colleges and universities.*
4. *Non availability of modern assistive technology in institutes of higher learning bars students from knowledge gain.*
5. *Lack of standard rules in the allotment of scribe during examination.*
6. *Non allotment of extra time and separate rooms to visually impaired students in rural areas.*
7. *Lack of availability of special coaching enters for students with special needs in the lines of SC & ST students.*
8. *Tokenism in scholarship, lack of timely notification and disbursement.*
9. *Lack of facilities for participation in college sports and games.*

Box 15**FGD at Chhatrapur, Ganjam (OH students)**

1. *Lack of barrier free college environment. This is a major concern of all students as it isolates them from most of the college activities being held at various premises.*
2. *Non – implementation of reservation policy in all colleges during admission.*
3. *Lack of special tutorials for students with disabilities.*
4. *Exemption of admission and examination fee, as introduced by higher education department, is not being universally implemented across all the colleges and universities.*
5. *Lack of awareness of disability laws among college authorities creates difficulty in explaining them and availing facilities as laid in the PWD Act 1995.*
6. *Tokenism in scholarship, lack of timely notification and disbursement.*
7. *Lack of escort allowance prevents many bright OH students from reaching colleges.*
8. *Non allotment of extra time in rural areas to severely OH students.*
9. *Lack of availability of special coaching enters for students with special needs in the lines of SC & ST students.*
10. *Lack of facilities for participation in college sports and games.*
11. *Non exemption of competitive examination fees.*

Educational Support Requirement

37.5% required physical access to building and transport. 26.4% had a need for braille material, 9.2% large print question paper, 4.3% audio material and 15.6% printed class notes. 7% had a mix of needs. Some required accessible laboratories, few personalized teaching, some requested more attention from teachers, few extra practical training hours and some coaching for entrance examinations (Table-44).

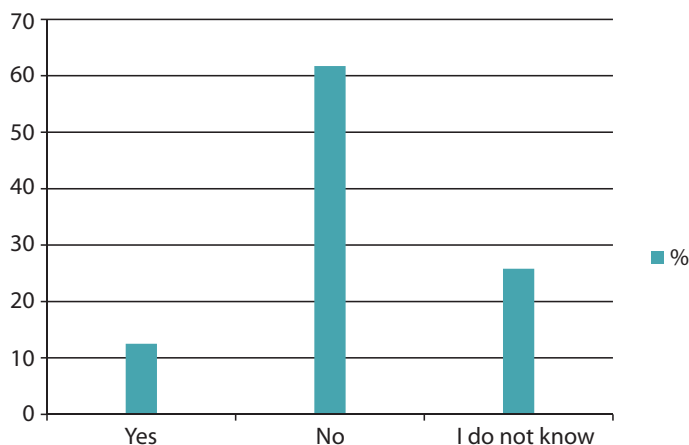
Table 44 : Educational support requirement

Requirements	Number	%
Large print question paper	27	9.2
Braille material	43	26.4
Audio Material	10	4.3
Printed class notes	28	15.6
Any other*	47	7
No Requirement	430	37.5

* Accessible laboratories, libraries, talking book libraries, personalized teaching, extra practical training hours and tutorials.

Educational aid received from college

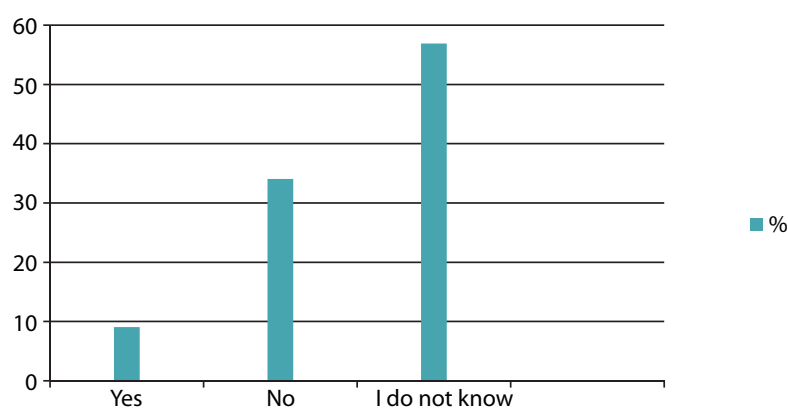
Only 12.5% of the students received the educational aid that they required from college. While 61.7% replied in negative, 25.8% said they were unaware of the fact that college should provide them educational support (Graph-19).



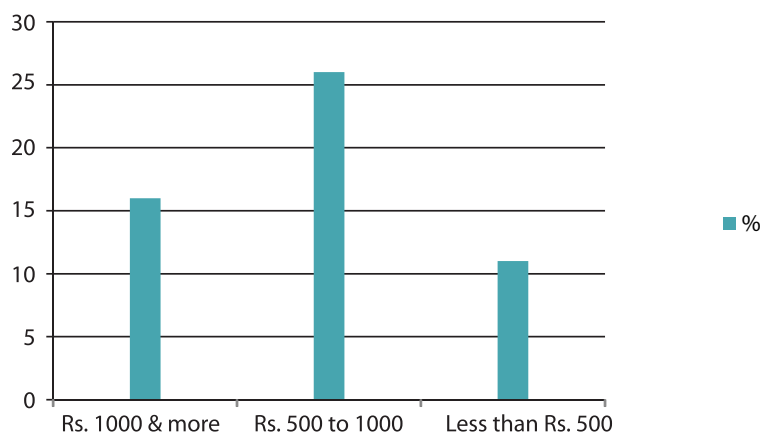
Graph 19 : Educational aid received from College

Scholarships

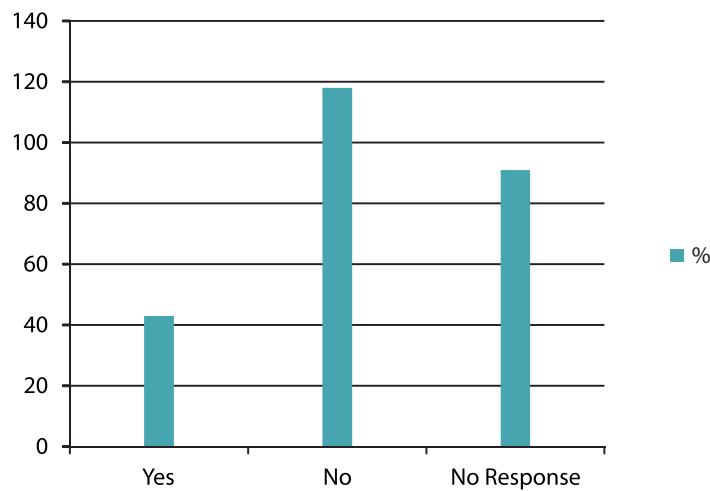
While 9% of students receive some or other educational scholarships (both from Government and Private Sources), 34% of the students do not receive any such scholarships. 56.9% of the students are unaware of the scholarships available to students with disabilities pursuing higher degrees (Graph-20). Of the 53 students receiving scholarships only 16 students received an amount of Rs. 1000 and more per month, 23 students received an amount between 500 to 1000 and rest 11 less than Rs. 500 (Graph-21). Of the 252 students who were aware of the scholarships, 43 said that it was disbursed regularly. 118 replied in the negative. 91 could not comment (Graph-22).



Graph 20 : Scholarship recipients



Graph 21 : Scholarship amount



Graph 22 : Scholarship disbursement

Recommendations

1. RTE must be translated to action by equipping all schools with special educators, resource rooms and ample learning teaching aids.
2. Different disabilities require different supports. A huge pool of skilled and trained personnel for supporting inclusive education must be created.
3. Curriculum must be made flexible to accommodate children with disabilities.
4. The existing handful of teacher trainers cannot reach the vast number of teachers working in SSA schools across the state. There is a need to explore alternatives such as training para-teachers, investing in pilot studies to develop tele-rehabilitation programmes and exploring strategies for distance education.
5. The training of general teachers at pre-service and in-service levels should address the issue of education of children with disabilities, such as classroom management; use of appropriate teaching methodologies; skills for adapting the curriculum; development of teaching-learning materials that are multi-sensory in nature; evaluation of learning; etc.
6. The preparation of CWSN in the form of early childhood intervention before enrolment is required to ensure that they do not drop out, are retained in schools, and compete equally with other children.

7. All special schools should be converted to preparatory centers and support circle for CWSN's transition and inclusion in mainstream schools
8. Modern assistive technology is highly essential in colleges and universities like laptops etc.
9. Obligatory hostel facilities needs to be introduced for all students with disabilities admitted.
10. Barrier free access in all academic institutions.
11. Special coaching centre need to be set up for the students with disabilities to prepare them for competitive examinations.
12. Exemption of examination of fee, provision of extra time during examination etc. introduced by higher education department, needs to be implemented in all the colleges and universities.

Voices

"I didn't like going to school, people laughed and that affected me because I didn't learn. I love dancing. I want to soon start my own school."

Mithilesh Patnaik, Down's Syndrome, Bhubaneswar

We want our children to go for inclusive education. But teachers discourage us. And in non-academic programs my child can be in the same class. But what will my son do in academic periods?

Rita Jena, Mother of autistic boy, Founder CATCH, Bhubaneswar

We are working under much constraints. Less than 15 days training is not sufficient to know how to teach the students with special needs. our low salary is discouraging us to work. With low salary much movement in the Panchayat is too difficult. some time we have to travel long distances. with our disabilities a motorized tricycle or Scooty would be helpful. Illiterate and unaware parents are a big challenge in our work. As schools do not have much facilities and teachers are not well trained, parents are reluctant to send their children to school. This is also a reason for less or no attendance of CWSN in schools. Most of the parents have expectation that they will get something, like monetary incentive, if their child with disability goes to school and they created lot of problems when IEVs visit their home. As each IEV has many schools to visit we do not get time to follow up and visit each child every day.

Vivekananda Santra, IEV Volunteer, Kundra Block, Koraput

Enhancing Banishree scholarship to one thousand rupees, notification for mandatory provision of scribes with incentives, hostel seats in priority and well equipped library for the VI students are basic requirements for higher education for SWD.

Pramodini Bisoi and Rupali Jena, students of RD women's College, Bhubaneswar



SSA School Rourkela



Special School Bolangir



There are 370 million persons with disabilities, 238 million of them of working age. Their unemployment rate is usually double that of the general population and often as high as 80% or more.

*Debra A. Perry,
'Disability issues in employment and
social protection', ILO Bangkok, 2002*



2.8 Livelihood, Employment and Poverty

In developing countries, 80% to 90% of persons with disabilities of working age are unemployed, whereas in industrialized countries the figure is between 50% and 70% (Washington Times, 2005). In the Asia and Pacific there are 370 million persons with disabilities, 238 million of them of working age. Their unemployment rate is usually double that of the general population and often as high as 80% or more (Perry, 2002). In EU there are approximately 40 million persons with disabilities, and of these 43% to 54% were of working age in 1998. Persons with disabilities are two to three times more likely to be unemployed than others (EUROPS, 1998). In India 74% of persons with physical disabilities and 94% of persons with mental retardation are unemployed (IDRM, 2005).

Enhancing employment opportunities for PWD is one of the main concerns of the disability sector. When one looks at the micro level, it may seem like there has been progress. There is increased awareness amongst corporates and people with disabilities. There has been pressure on the Government to implement PWD Act, 1995. Even though there was no law mandating the private sector to employ disabled people, some companies have taken proactive measures to employ disabled people. The picture seems positive! However, the finding of the World Bank Report 'People with Disabilities in India: From Commitments to Outcomes' released in 2007, states 'the employment rate of disabled people has actually fallen from 42.7% in 1991 down to 37.6 % in 2002.' According to the employment projection given in the Eleventh Plan, in the Chapter 'Employment Perspective and Labour Policy', '58 million job opportunities will be created in the Eleventh Plan period leading to a reduction in the unemployment rate to below 5%. Over the longer period up to 2016–17, spanning the Eleventh and Twelfth Plan periods, the additional employment opportunities created are estimated at 116 million. The unemployment rate at the end of the Twelfth Plan period is projected to fall to a little over 1%.' There is a wide gap between the employment rate of people with and without disabilities in the country. Therefore, the above target for bringing down the unemployment rate cannot be achieved without addressing the employment issues of PWD. It would require proactive initiative on the part of all concerned to ensure that disability is included in the employment programs of the Government and the private sector.

The departments responsible for employment in the state are Labor & Employment, commerce, Industry, Panchayati Raj and Rural Development. There is one special Employment Exchange for PWD in the State.

PWD Act 1995 has many statutes on employment (Box-16).

Box 16**Chapter VI - Employment (PWD Act 1995)**

32. *Appropriate Governments shall—*

- a. *Identify posts, in the establishments, which can be reserved for the persons with disability;*
- b. *At periodical intervals not exceeding three years, review the list of posts identified and up-date the list taking into consideration the developments in technology.*

33. *Every appropriate Government shall appoint in every establishment such percentage of vacancies not less than three per cent. for persons or class of persons with disability of which one per cent. each shall be reserved for persons suffering from—*

I. Blindness or low vision;

ii. Bearing impairment;

iii. Loco motor disability or cerebral palsy, in the posts identified for each disability:

Provided that the appropriate Government may, having regard to the type of work carried on in any department or establishment, by notification subject to such conditions, if any, as may be specified in such notification, exempt any establishment from the provisions of this section.

34.(1) *The appropriate Government may, by notification. Require that from such date as May be specified. By notification. The employer in every establishment shall furnish such information or return as may be prescribed in relation to vacancies appointed for person, with disability that have occurred or are about to occur in that establishment to such Special Employment Exchange as may be prescribed and the establishment shall thereupon comply with such requisition.*

2. *The form in which and the intervals of time for which information or returns shall be furnished and the particulars, they shall contain shall be such as may be prescribed.*

35. *Any person authorized by the Special Employment Exchange in writing, shall have access to any relevant record or document in the possession of any establishment, and may enter at any reasonable time and premises where he believes such record or document to be, and inspect or take copies of relevant records or documents or ask any question necessary for obtaining any information.*

36. *Where in any recruitment year any vacancy under section 33, cannot be filled up due to non-availability of a suitable person with disability or, for any other sufficient reason, such vacancy shall be carried forward in the succeeding recruitment year and if ;r the succeeding recruitment year also suitable person with disability is not available, it may first be filled by interchange among the three categories and only when there is no person with disability available for the post in that Year, the employer shall fill up the vacancy by appointment of a*

person, other than a person with disability: Provided that if the nature of vacancies in an establishment is such that a given category of person cannot be employed, the vacancies may be interchanged among the three categories with the prior approval of the appropriate Government.

- 37. (1) Every employer shall maintain such record in relation to the person. With disability employed in his establishment in such form and in such manner as may be prescribed by the appropriate Government.*
- 2. The records maintained under sub-section (1) shall be open to inspection at all reasonable hours by such persons as may be authorized in this behalf by general or special order by the appropriate Government.*
- 38. (1) The appropriate Governments and local authorities shall by notification formulate schemes for ensuring employment of persons with disabilities, and such schemes may provide for-*
 - a. The training and welfare of persons with disabilities;*
 - b. The relaxation of upper age limit;*
 - c. Regulating the employment;*
 - d. Health and safety measures and creation of a non-handicapping environment in places where persons with disabilities are employed;*
 - e. The manner in which and the person by whom the cost of operating the schemes is to be defrayed; and*
 - f. Constituting the authority responsible for the administration of the scheme.*
- 39. All Government educational institutions and other educational institutions receiving aid from the Government, shall reserve not less than three per cent seat for persons with disabilities.*
- 40. The appropriate Governments and local authorities shall reserve not less than three percent. in all poverty alleviation schemes for the benefit of persons with disabilities.*
- 41. The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development, provide incentives to employers both in public and private sectors to ensure that at least five per cent. of their work force is composed of persons with disabilities.*

UNCRPD in its Article 27 on 'Work and employment' mandates States Parties to recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible to persons with disabilities. It also calls for prohibition discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy

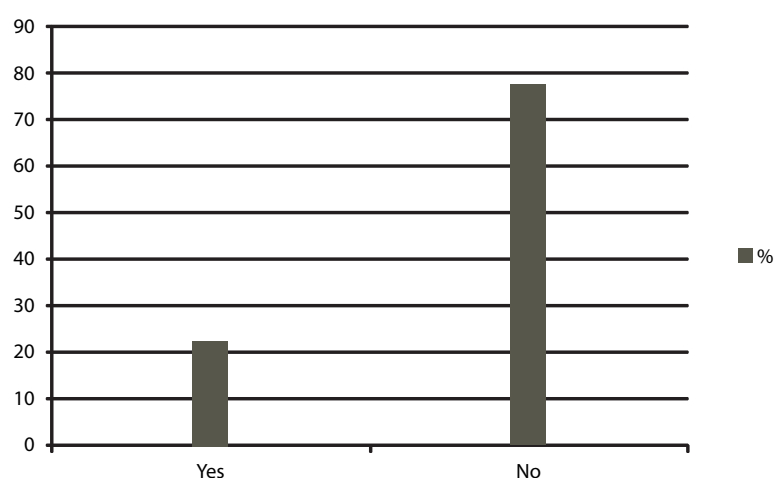
working conditions. There is a clause for promotion of opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business; and it mandates States Parties to ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labor.

2.8.1 Employment and Livelihood

In our study there were 2911 who had the potential, health and age to earn a living. However, the situation is grim in Odisha with only 22.2% earning a living and the rest 77.8% surviving as dependents (Table-45 and Graph-23).

Table 45 : Number of PWD who earn a living

Responses	Number	%
Yes	645	22.2
No	2266	77.8

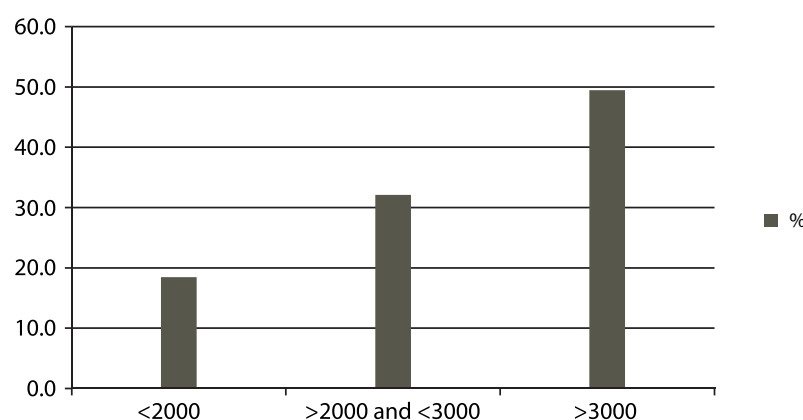


Graph 23 : Average monthly income of PWD

The earning cannot be termed as a 'earning' rather can be regarded as a supplement to family income as the average income of a PWD is between 2000 to 3000 rupees per month. Receipt of the disability pension increases the monthly income by a narrow margin (Table-46 and Graph-24).

Table 46 : Average monthly income of PWD

Responses	Number	%
<2000	119	18.4
>2000 and <3000	207	32.1
>3000	319	49.5
Total	645	100



Graph 24 : Number of PWD who earn a living

Looking at the sectors of employment one finds an aggregation in small business and daily wage earning. The category 'Other' is a mix of accountant, DTP Operator, call centre workers, store room in-charge, electrical worker, plumber, gardener, sweeper, receptionist, phone attendant and peon. 45% (291) run small business and 29% (191) are daily wage earners (Table-47).

Table 47 : Livelihood sectors

Responses	Number	%
Placement in NGOs	12	1.9
Agrarian	73	11.3
Small business	291	45.1
Daily wage labour	191	29.6
Teaching and tutions	38	5.9
Social worker	1	0.2
Short term project	4	0.6
Professional	4	0.6
Other	25	3.9
No Response	6	0.9
Total	645	100

13% (84) are employed in various establishments (Table-48). Of these only 29.7% were employed in regular sectors with credibility, 14% were engaged in NGOs and for 45% tutions were source of income (Table - 49). This brings to the fore an almost scary picture. When the PWD themselves are so poorly educated what quality of learning would they be imparting?

Table 48 : Number of PWD in job

Responses	Number	%
Yes	84	13.0
No	561	87.0
Total	645	100

Table 49 : Job categories

Responses	Number	%
Placement in NGOs	12	14.3
Teaching most absorbed in SSA and tutions	38	45.2
Social worker	1	1.2
Short term project	4	4.8
Professional	4	4.8
Other	25	29.8
Total	84	100

Self employment is a better option. PWD can be encouraged to go in for production related business. The National Trust has recently started a Marketing Federation ARUNIM. It is established as a non-profit society to serve the interest of its members through marketing initiative for the products made by persons with disabilities particularly those disabilities that are covered under National Trust Act. Uddyam Prabha (Incentive) Scheme has been initiated for promoting vocational and economic activities for persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities through interest subsidy. Interest incentive upto 5% for BPL and 3% for other categories is to be given per annum upto 5 year on a loan amount of upto Rs.1 lakh. However, Odisha has not made any inroads into this program.

The 291 who ran small business included both individual proprietors and members of self help groups (Table-50). Of them 52.6% were owners of paan (betel leaf) shop. Grocery shops came next (13.4%) followed by 'others' which included self- help group activities. The seed capital was mostly from 'own money', which was contribution of parents, family members, friends and personal savings. SHG groups were linked to banks. NHFDC loan came at a low 7.6% (Table-51). However, the negative aspect was 46% of the ventures do not earn a profit (Table-52 and Graph-25) which reflects the possibility of its closure in future.

Table 50 : Small business by PWD

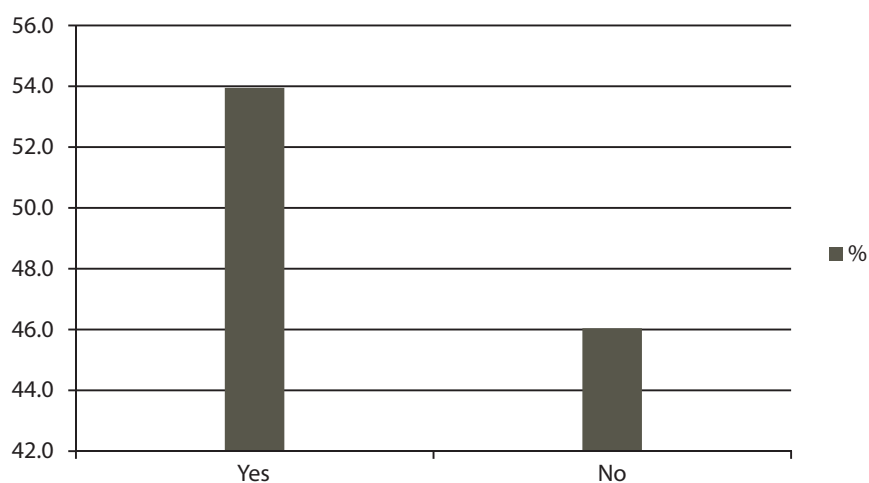
Responses	Number	%
Grocery shop	39	13.4
Beetle shop	153	52.6
OMFED booth	4	1.4
Dealership	13	4.5
Hotel/Sweet shop	18	6.2
Cycle shop	7	2.4
Tailoring	21	7.2
Other	36	12.4
Total	291	100

Table 51: Source of seed capital for small business

Responses	Number	%
NHFDC loan	22	7.6
NGO	11	3.8
Money lender	16	5.5
Own money	206	70.8
Bank	30	10.3
Other	6	2.1
Total	291	100

Table 52 : Profit in small business

Responses	Number	%
Yes	157	54.0
No	134	46.0
Total	291	100



Graph 25 : Profit in small business

Of the 191 daily wage earners only 39% got work for 30 days. 17.5% earned for 20-25 days, 8% 10-15 days and only 0.7% worked for less than 10 days (Table-53).

Table 53 : Number of days of wage earning

Responses	Number	%
30 days	114	39.2
20-25 days	51	17.5
10-15 days	24	8.2
Less than 10 days	2	0.7
Total	191	65.6

Livelihoods approach to development focusing on both land and non-land based development and supporting migration to urban areas where it is a desired option, offers some prospect of including the disabled in development activities. This requires the conscious inclusion of the disabled by others in the community and by government and NGO staff working with communities. Livelihoods approaches can include the disabled in participatory development initiatives in the community as a whole and provide particular income earning opportunities, for specific groups of the disabled so that there is a chance

for the whole community to benefit from development. Rationale of SL approach is its inclusiveness in CD. DFID-supported APRLP covers five districts in Andhra Pradesh. The target group for the project are the rural poor in those districts, which is likely to include least 150,000 profoundly disabled people in the project's target population, and probably many more affected by some un-enumerated form of disability. Odisha needs such initiatives.

2.8.2 Vocational Training

Vocational Rehabilitation Center (VRC) established in the state capital by Ministry of Labour and Employment makes vocational assessments of PWD and provides short term training. It also provides limited job placement services. However, what is required is upgradation of the skills imparted along with shifts in labor demand. An expanding number of NGOs have become active in vocational training of PWD and direct employment generation, but the majority with no accreditation process. The majority of NGOs are oriented towards skills for sheltered, group and self-employment rather than employment in the organized sector. There are several common weaknesses of NGO programs. First, most have a strong urban bias, as well as under-representation of women trainees. Second, many NGOs acknowledge a lack of qualified trainers. Third, as in the public sector, NGOs frequently failed to undertake sufficient assessment of the local labor market conditions in determining courses for PWD.

As compared to VRC Bhubaneswar more number of respondents were aware of VTC run by NGOs (Table-54 and Table-55). 15.5% were aware of VTC and 24.7% were aware of VTC run by NGOs. Among graduates and post graduates there was a greater awareness of these centers.

Table 54 : Awareness of VRC Bhubaneswar*

Educational Level	No. of Respondents	Number	%
Class 8th	588	0	0
Matriculate	377	29	7.9
Graduate	138	23	16.7
Post graduate	39	5	12.8
Technical	9	0	0
Total	1151	57	15.5

* Awareness among respective age groups

Table 55 : Awareness of VTC run by NGO*

Educational Level	No. of Respondents	Number	%
Class 8th	588	18	3.1
Matriculate	377	24	6.5
Graduate	138	37	26.8
Post graduate	39	11	28.2
Technical	9	1	5.6
Total	1151	91	24.7

* Awareness among respective age groups

The quality of training being imparted by NGOs is not upto the standard. During FGD it became clear that most NGOs train in some archaic skills like candle making, agarbatti making and chalk making which has not much relevance in the present time. Lack of equipments is a concern in both VRC and VTC (Table - 56 and Table-57).

Table 56 : Quality of training in VRC Bhubaneswar

Responses	Number	%
Good training	32	56.1
Poor training	4	7
No trainers	2	3.5
Lack of equipments needed for training	19	33.3
Total	57	100

Table 57 : Quality of training in VTC run by NGOs

Responses	Number	%
Good training	9	9.9
Poor training	28	30.8
No trainers	27	29.7
Lack of equipments needed for training	27	29.7
Total	91	100

The vocational training being provided is not leading to many jobs. Only 26.3% of those who have passed out from VRC, Bhubaneswar have got jobs on the basis of their training there. The VTC trainings are not leading to any jobs (Table - 58).

Table 58 : Is vocational training leading to job placements?

Responses	Number	%
VRC	15	26.3
VTC	2	2.1

2.8.3 Poverty

The relation between poverty and disability is commonly accepted as a vicious circle and it is widely hypothesised that it is a two way relationship i.e. disability increases the risk of poverty and conditions of poverty increase the risk of disability. The objective of this analysis was mainly to understand the relationship between poverty and disability in the PWD population of India. The association between poverty and disability has been well documented (U.S. Census Bureau, 2004; Wittenburg & Favreault, 2003, Elwan, 1999) in the literature. The relationship is, in general, found to be causal (Braithwaite and Mont, 2008, Lustig et al., 2007; DFID, 2000; Moore and Yeo, 2003; Yeo, 2001). It is argued that though not all disability is caused by poverty, poor people who suffer from malnutrition and in lack of adequate access to health services including maternal care and trauma services, are more likely to suffer from disability which further ensure their exclusion and marginalization by reducing their opportunities to contribute productively to the household and to the community, which in turn increases the risk of poverty (DFID, 2002, and Moore and Yeo, 2003) provide specific mechanism how the vicious circle between poverty and disability exists and work. DFID (2000) describes a vicious circle and the causal link between disability and poverty suggest that in one hand the poverty increases the likelihood of injury and impairment and hence the risk of disability; on the other hand the exclusion of disability leads to greater rates of poverty. Other studies also suggest that poverty increases the risk of disability through social role devaluation (Wolfensberger, 2000), environmental risk factors (Evans, 2004; Link & Phelan, 1995), negative group influences (Durlauf, 2001), and weakened sense of coherence (Antonovsky, 1987, 1991). Recently Lustig et al. (2007) emphasize that poverty limits access to resources that finally leads to a chronic health problem or disability. sense of coherence (Antonovsky, 1987, 1991). Recently Lustig et al. (2007) emphasize that

poverty limits access to resources that finally leads to a chronic health problem or disability. Research shows that this vicious circle varies as well within and between cultures and contexts, but is generally acknowledged to be strong. Thus, the link between poverty and disability may be attributed to the discrimination, social exclusion and denial of rights together with lack of access to basic services.

The poverty or poor exists where some persons fall short of reasonably defined minimum levels of wellbeing such as access to certain consumption or income levels, housing, health and education facilities and certain rights recognized according to standards of human needs and socio economic conditions of the society. Rampant poverty among the PWD households is amply demonstrated by a measly 22.2% eking out a living and earning a very the poor income (on an average about 2-3000 rupees per month). Non-profitability of businesses is a potent indicator of vicious hands of poverty on its way to gripping more PWD households. When enquired about having enough money to take care of family only 9.9% replied in the positive. 44.1% refrained from giving any answer, either kept quiet, made a joke or looked away (Table-59). There is no or meagre saving. Only 17.9% save (Table-60). Mostly saving was utilized for health related activities or for repayment of loan (Table-61).

Table 59 : Enough income to take care of family needs

Responses	Number	%
Yes	64	9.9
No	297	46.0
No response	284	44.1
Total	645	100

Table 60 : Savings

Responses	Number
Total PWD earning	645
Total PWD saving	116

Poverty alleviation programs and PWD

According to Panchayati Raj Department in 2009 and 2010, 4003 PWD, from across Odisha, got 100 days job. As per our findings, only 7.4% PWD have got 'Mo Kudia', 25.9% IAY and

14.8% work in SJSY. If we consider PWD under BPL category, then the figures stand at 8.7%, 30.4% and 17.4% respectively.

Table 61: Utilization of savings

Use of Saving	Number	%
Health	56	48.3
Loan payment	29	25.0
Land purchase, house construction and repair	5	4.3
Cloth	2	1.7
Festival & social obligation	2	1.7
Buying luxury items	5	4.3
Other*	17	14.7
Total	116	100

* Education, personal expenses, food, plantation etc.

Around 50% households covered in the study live in mud houses (Kacha house) (Table-62). During their discussion with surveyors 80% of households living in mud houses that they had no access to electricity which clearly indicate to the fact that the maximum percentage of households covered in the study are extremely poor and marginalized. Disability coupled with poverty makes PWD the most marginalised. There is no escape from this vicious cycle. The Right to Food campaign and governments food subsidy programs must addressed PWD without consideration of APL and BPL category to bridge the gap between chronic poverty and moderate living.

Table 62 : Housing

Type of House	Number	%
Pucca/brick	1129	27.2
Mud	2052	49.4
Mud with tile roof	859	20.7
Others	112	2.7

* In different terrains the roofing pattern changes from tiles, palm leaves to tin shades. Some houses in slums were made up bamboo, sacks and polythene.

Recommendations

1. Identification of jobs should be replaced with job analysis. Job analysis describes the job and not the person. Job Analysis would require each job to be looked at and the job descriptions will have to be written in detail. For instance, if a job requires travelling, it should be mentioned clearly as to how much travelling is required to be done, so the person can choose if she/he can do that travel or not. It cannot simply assume that people with both leg disabilities cannot travel. There should also be scope for reasonable accommodation/workplace solutions. If the person can demonstrate her/his ability to perform the essential skills with or without accommodation, she/he should be given the opportunity.
2. Reservation needs to be reviewed and reformed. If a quota approach is retained, it should be based on a share of all posts in public agencies and discontinue the practice of “identified posts”.
3. Creation of a Monitoring Committee comprising of 2 Heads of Departments, 3 elected representatives and 5 disability activists/disabled individuals. They should fill up all government departments with 3% disabled employees, starting with state secretariat.
4. The Government should also review whether special employment exchanges should be integrated into the regular exchange network.
5. There must be a systematic engagement with the private sector to assess labor market demand and move away from the current focus on public sector employment.
6. Regular assessment of labor market demand should be followed up with modification of existing or addition of new vocational training programs.
7. In skill development and vocational training focus should be on creating skilled persons or the 20 high growth Industries. Ten high growths sectors on Manufacturing side — (i) automobile and auto components (ii) electronics hardware (iii) textiles and garments (iv) leather and leather goods (v) chemicals and pharmaceuticals (vi) gem and jewelry (vii) building and construction (viii) food processing (ix) handlooms and handicrafts (x) building hardware and home furnishings. On the Services side, ten high growth sectors - (i) ITs or software services sector (ii) ITeS-BPO services, (iii) tourism, hospitality and travel trade (iv) transportation/logistics/warehousing and packaging (v) organized retail (vi) real estate services (vii) media, entertainment, broadcasting, content creation, animation (viii) healthcare services (ix) banking/insurance & finance (x) education/skill development services.



OH, Bamboo Appliances, Jagatsinghpur



HI, Tailoring



Lack of clean water and sanitation keep people poor; unhealthy and unable to improve their livelihoods. Disabled people have the least access to these services, which compounds their isolation, poor health and poverty.

*H.Jones and B. Reed,
Water & Sanitation for disabled and
other vulnerable groups',
Loughborough University, 2005, UK*



2.9 Health, Water and Sanitation

Poor hygiene, inadequate quantities and quality of drinking water and lack of sanitation facilities cause millions of the world's poorest people to die from preventable diseases each year. PWD have the least access to these services, which compounds their isolation, poor health and poverty. A lack of accessible sanitation facilities can have a double impact. For example, in communities where women defecate at night, moving around in the dark is extra hazardous for a disabled woman. Improved nutrition, food security, access to health care, clean water, sanitation and immunization will empower PWD just as access to transport system leads to safer working and living environment.

The PWD (Equal Opportunities, protection Of Rights And Full Participation) Act, 1995 in its Chapter IV, Section 25 (e) mentions health and sanitation briefly, as the Act's major focus remains early detection and prevention of disability (Box-17).

Box 17

Chapter IV – Prevention and Early Detection of Disabilities (PWD Act 1995)

25. *Within the limits of their economic capacity and development, the appropriate Governments and the local authorities, with a view to preventing the occurrence of disabilities, shall-*
- e. *Sponsor or cause to be sponsored awareness campaigns and is disseminated or cause to be disseminated information for general hygiene. Health and sanitation.*

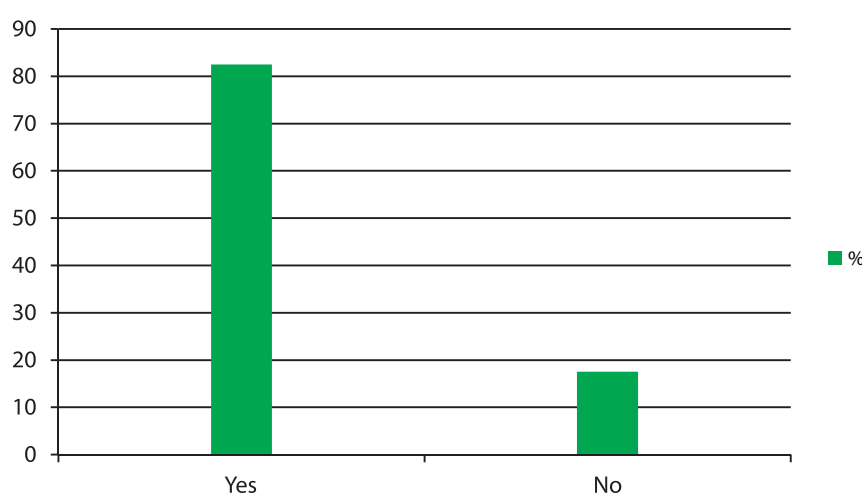
UNCRPD talks elaborately in its Article 25 about health. It asserts that PWD have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. It further mandates States Parties to take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, it emphasizes provisions for the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs; 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, including among children and older persons; and health services as close as possible to people's own communities, including in rural areas. In its Article 28 (adequate standards of living and social protection) it elaborates ensuring of equal access by persons with disabilities to clean water services.

2.9.1 Health

Disability does not necessarily equate to poor health. For example, in the early stages of disability associated with paraplegia, the affected person may be considered in poor health and may have a greater need for medical and health care, but once their condition is stable they may enjoy good health (AIHW, 2004). However severity of disability aggravates health related problems. Persons with disabilities have a narrow margin of health. The disabled are, on average, much more likely than non-disabled persons to experience a broad range of acute health problems. Research found these problems often do not surface until after the disabled person has been discharged from hospital. Further, communication barriers between people with intellectual disabilities and health sector personent often impede the process of diagnosis, essential in reporting health problems (Lennox et al, 1997). Research found PWD with mental health problems, cerebral palsy and other developmental disabilities suffer the most health problems. 82.5% PWD have access to health facilities (Table-63 and Graph-26).

Table 63 : Access to health facilities

Responses	Number	%
Yes	3426	82.5
No	726	17.5
Total	4152	100



Graph 26 : PWD Access to Health Facilities

PWD visit multiple service providers for health ailments. There is a distinct difference in the type of health facility PWD visit to address health problems in rural and urban areas. But the general movement is towards government health facilities, be it district hospital, PHC, CHC, ICDS centers etc (Table-64). In urban areas 45.8% PWD visited district hospitals (or main government hospital), 9.9% went to PHC/CHC, 13.9% took medicines by consulting medicine shop owners/sellers and 7.7% went to private clinics and doctors. Among other forms, 2.1% Kabiraj (Vaidya), 9.1% homeopathy and 9.6% preferred medical camp by NGOs and charitable organizations, Unani, Siddhi, Reiki, Yoga, Pranayam, magnetic treatment, acupuncture and naturopathy. Faith healers provide healing to 2% of the population (Table-65). Among rural population only 13.8% PWD frequent district hospital. 37% visit PHC/CHC and 11.2% depend on Anganwadi workers/ ICDS Centre/ Mobile Van/ Dai and quacks. Few of them also directly go to the three medical colleges i.e. SCB (Cuttack), VSS (Burla) and MKCG (Berhampur). Few families (southern and western Odisha) took their disabled members to nearby hospitals in Vijag. Among other forms of health care 4.4% went to Kabiraj (vaidya/hakim), 7.8% to homeopaths and 4.9% to faith healers. 11.8% depended on medicine stores and 1.1% only went to private doctors (Table-66).

Table 64 : Type of health facility PWD use (N = 3949)*

Type of health facility	Urban(N)	Urban %	Rural (N)	Rural %	Total(N)	%
Kabiraj	40	2.3	569	5.9	609	5.4
District Hospital	823	46.9	1378	14.3	2201	19.4
PHC/CHC/Rural Hospital/ Sub Centers	187	10.7	3764	39.2	3951	34.8
Faith healer	37	2.1	637	6.6	674	5.9
Homeopath	173	9.9	904	9.4	1077	9.5
Medicine shop	166	9.5	1082	11.3	1248	11.0
Private doctor/ Clinic/ Health Worker	154	8.8	147	1.5	301	2.6
Other**	174	9.9	1132	11.8	1306	11.5
Total	1754	100.0	9613	100.0	11367	100.0

* PWD use multiple facilities

** Anganwadi/ICDS Centre/Mobile Van/Dai/Quack/ Siddh/Unani/Yoga/Pranayam/ magnetic treatment/acupuncture/naturopathy and medical colleges.

Table 65 : Type of health facility urban PWD use (N = 3949)*

Health facility	Number	%
Kabiraj	40	2.3
District Hospital	823	46.9
PHC/CHC/Rural Hospital/Sub Centers	187	10.7
Faith Healer	37	2.1
Homeopath	173	9.9
Medicine Shop	166	9.5
Private Doctor/ Clinic/ Health Worker	154	8.8
Other**	174	9.9
Total	1754	100

* PWD use multiple facilities

** Anganwadi/ICDS Centre/Dai/Quack/Siddh/Unani/Yoga/Pranayam/Magnetic Treatment/ Acupuncture/Naturopathy and Medical colleges

Table 66 : Type of health facility rural PWD use (N = 3949)*

Health facility	Number	%
Kabiraj	569	5.9
District Hospital	1378	14.3
PHC/CHC/Rural Hospital/Sub Centers	3764	39.2
Faith Healer	637	6.6
Homeopath	904	9.4
Medicine Shop	1082	11.3
Private Doctor/ Clinic/ Health Worker	147	1.5
Other**	1132	11.8
Total	9613	100

* PWD use multiple facilities

** Anganwadi/ICDS Centre/Mobile Van/Dai/Quack/ Siddh/Unani/Yoga/Pranayam/Magnetic treatment/Naturopathy, Medical colleges and NGO camps

It was found that the maximum suffering was caused by malaria (35%) followed by anaemia (19.4%), fever (14.2%), Diarrhoea (6.9) and TB (3.1%) (Table-67). In this context 'others' assumes significance as it included among others UTI, RTI, arthritis, fever, fall, cuts and injuries. This needs more research as different categories reflected different health issues. Among WWD and wheel-chair users UTI was rampant. Fever and chest infections were recurrent in persons with MR and SCI. In deaf population ear infection was common. Falls, cuts and injuries was widespread among MR, OH and VI.

Table 67 : Common health ailments (N=12456*)

Diseases	%
Fever	14.2
Diarrhoea/Dysentery	6.9
Anaemia	19.4
Malaria	35
Tuberculosis	3.1
Other**	21.5

* People reported multiple ailments suffered by them in one year's time.

** Cold and Cough/TB/Asthma/BP/Diabetes/Seizures/Cancer/Rheumatism/ Gynecic Problem/ Headache/Ear Infection/ UTI/RTI/Injuries and Burn

2.9.2 Water and Sanitation

Lack of clean water and sanitation is the important risk factor in terms of global burden of disease, after mal nutrition. Women and children are the main victims. The critical importance of unrestricted access to clean drinking water and basic sanitation for all is highlighted in Millennium Development Goal 7, which calls for the reduction by half of the proportion of people without such access by 2015. Unfortunately, little attention has been paid to the needs of such access for the one billion people living with a disability worldwide, despite the fact that the right to equal access for all international development initiatives is guaranteed in the new United Nations Convention on the Rights of Persons with Disabilities. Disabled people often have the poorest access to water and sanitation because of physical barriers such as steps and inappropriate design, as well as attitudinal barriers that keep them away from public facilities for personal or social reasons (Dzikus & Bhattacharjee, 2008).

Box 18

Excerpt from Access to Water and Sanitation for the Disabled or the Differently Aabled,” Presentation by Andre Dzikus, Chief, Water, Sanitation and Infrastructure Branch, Section II, and Debashish Bhattacharjee, Human Settlements Officer, Water, Sanitation and Infrastructure Branch, Section II, 22 May 2008, Addis Ababa Ethiopia

2. *Inclusive facilities benefit the entire community because when people with disabilities get water-related infections, their families and communities become at risk, which also impacts on the local economy.*
3. *Disability, poor access to water and sanitation and poverty are interrelated, for instance, polio and water contamination by fluoride and arsenic all cause disability*
4. *Diarrhea, which is often caused by lack of access to clean water, is responsible for 5% of health loss from disability*
5. *People with disabilities may need more water for washing because of their disability – for instance, some people may crawl or fall frequently*
7. *Programs that provide public water and sanitation facilities often do not consider the range of users trying to access services⁸. Development organizations may overlook people with disabilities in their water and sanitation projects, while disability organizations rarely address water and sanitation issues.*

Odisha one of the poorest states of India since 1979. Orissa has a population of closed to 37 million of which 86% live in Rural areas(Census 2001). According to BISWA (has been identified as a 'Key Resource Center' of Orissa State Water and Sanitation Mission for eight districts: Sambalpur, Jharsuguda, Bargarh, Sonepur, Deogarh, Sundargarh, Mayurbhanj and Boudh under the Total Sanitation Campaign) less than 20% of the rural population of Orissa has access to protected water, less than 1% to piped water supply, and less than 5% to sanitation. The reason behind chronic poverty and under development in Orissa ,is due to non privileges of proper hygiene practice and proper sanitary provision in rural areas India it is found in early 90's that ill-health and loss of productivity life are among the root causes. Over 80% of the instances of morbidity and mortality are caused by unhygienic practice an abysmal attitude towards disposal of human waste and the resultant wide spread contamination of drinking water. Lack of access to safe drinking water is a major cause of ill health and loss of productivity. To address this issue Odisha State Water and Sanitation Mission (OSW&SM) has been constituted since 2002 and it works towards enhancing access to better water supply and sanitation facilities in rural areas. 86.4% PWD have access to a

permanent source of water, only water not clean drinking water (Table-68). But they struggle in the summer and during natural calamities like flood etc. The 'safety' of this water is a question to ponder on. The water stated as clean by respondents was on the basis of normal visibility. This study did not look into the quality of water that differentiates drinking water from any other water. In many habitations there was high iron content (Jajpur and Khurda) or salinity (Balasore) or fluoride (Nuapada and Nayagarh) and chloride pollution and; also bacteriological contamination.

Table 68 : Access to clean water

Area	Number	%
Rural	2978	84.8
Urban	610	95.0
Total	3588	86.4

Table 69 : Source of water supply

Source of Water supply	Number	%
Supply tap water	469.0	11.9
Well	999	25.3
Tubewell/Borewell	2090	52.8
Pond	279	7.1
Combination of sources	118	3

Sanitation involves waste disposal systems, water supply, sewerage networks and preserving ecology. And, on all these counts, India is very deficient. The severity of the problem in India could be judged from the fact that hardly 33% population has sanitation facility available. In rural area percentage coverage is only 22%, however it is 59% in urban areas. (WHO/UNICEF Sanitation Assessment Report 2004). The toilet facility is available in varying degrees to the urban households in different States and Union Territories. Unfortunately the lowest percentage of 49.27 is in Odisha and the highest percentage of 96.32 in Tripura.

Only 21.7% PWD use latrines (Table-70). 70.4% go for open air defeacation. Many of the households visited had latrines but they remained unused. This was mainly due to the poor construction work and lack of completion of many latrines. Few of the complete constructions were in very unhygienic conditions due to lack of use and maintenance.

Table 70 : Kind of latrine

Type	Number	%
Pit	490	11.8
Pucca (water sealed)	276	6.6
Pacca (unhygienic)	365	8.8
Open defecation	3021	72.8

Recommendations

1. Government and society must ensure that all health care rights, entitlements and benefits are universally available with due consideration accorded to gender, age and socio-economic status; for the health care of PWD during times of natural disasters and other situations of risk; and for sexual and reproductive health especially of women with disabilities.
2. PWD should be provided quality but free or affordable health care as close to their communities, especially access to all primary care services, within rural areas. They should be provided free transport to hospitals.
3. For the minimization and prevention of further disabilities requisite education and information must be provided closest to home.
4. All establishments shall provide health and life insurance to persons with disabilities on an equal basis with others.
5. There is a wide knowledge gap in the area of water and sanitation for PWD and there is a clear need for small action research pilot projects implemented with collaboration between the government, research institutions, corporate and disability sector, which will help to build up a body of knowledge on the issue, enable the sectors to learn from each other, and develop better dialogue and understanding of their different roles in addressing the issue.

Voice

Most people avoid going to hospitals because they do not have access to transport.

Pradip Aggarwal, OH, President DAN, Nuapada





Drinking water from river



OH Man in Slum

The international goal to achieve universal access to reproductive health cannot be achieved unless persons with disabilities are brought into the mainstream and included in policies and programmes to improve sexual and reproductive health.

*Thoraya A. Obaid
2009, Washington D.C.
UNFPA Executive Director
(Emerging Issues -Sexual &
Reproductive Health of PWDs)*



2.10 Marriage and Parenthood

The essence of marriage is companionship. It is a union between two consenting adults and it involves adjustment and carrying on day to day responsibilities of life. It also involves an ability to plan for the future. The degree of difficulty a PWD encounters in developing relationships depends on the individual person and his or her family, as well as on the severity level of the handicap. This is hardest for adults who need the most care. Although disabled men and women constitute the most marginalised of almost every society, the gender imbalance still exists. Disabled women are more likely than disabled men to be poorer, achieve lower educational outcomes, face medical interventions to control their fertility and experience sexual violence (Meekosha, 2004). Furthermore, women have unique sexual health risks such as unplanned pregnancy, higher susceptibility to sexually transmitted infections and cervical and breast cancer.

Regarding marriage of PWD, negative and stereotyped attitudes in our society, where any variation from a normally accepted archetype is seen as a marked deviation, see the impaired body as a symbol of imperfection and reject it from marriage as an institution. Secondly, the disability movement in India is focused on social change in terms of entitlements like inclusive physical environmental access, education, employment, and so on. As basic needs are not yet fully met issues of marriage and sexuality do not find a visible space in the disability discourse in India. Third, disabled women are considered asexual and not capable of long-term relationships. Similarly, children are taken away from disabled persons, as they are not deemed fit and responsible enough to be mothers. According to the 1995 UNDP Human Development Report, women with disabilities are twice as prone to divorce, separation, and violence as able-bodied women. Disabled women face discrimination in the adoption process, in the provision of foster care and in getting custody of their children after divorce. There is reluctance among WWD to marry and bear children (Swabhiman, 2005).

Access to family planning education, assistive reproduction and family welfare programmes is vital to ensure that persons with disabilities can exercise their reproductive rights with maximum support in order to enjoy their right to found a family. This principle is an inherent component of Article 23 of the CRPD. The Government of India has implemented various measures in law, policy and schemes to ensure access to such information. The Government of India has also adopted various policies and programmes with respect to family planning education and enforcing reproductive rights of all target groups. These include the National Population Policy, 2000, family planning education schemes and family welfare schemes.

Box 19**Marriage & Child bearing****(Excerpt from Swabhiman research work, 2005)****Table 71 : Marriage and child bearing**

Type of Disability	Want to Marry	Want to have children
OH/VI/HI	58	44.2
MC	26.8	21.6

If a woman becomes disabled after her marriage, she knows that her husband will leave her for another wife. Or if she has children she will be judged incapable of looking after them. The children will be put in the care of grandparents. 32% of women in our study group were married among OH, 38.2 among VI, 50 among HI and 18.6 among the MC. Thus altogether 30.5% respondents were married. Here, too, the majority of disabled women are also discriminated, as from the outset women are judged by their physical looks and not by their qualities as human beings. Disabled women do not meet the set standards, and their sexuality is barely recognised. The possibility of being considered asexual, and therefore of being deprived of their right of bringing up a family, childbirth, adoption, and housekeeping, etc, is directly proportional to how evident the disability is.

2.10.1 Marriage

So far as laws of India relating to marriage the various laws enacted by the government for the various communities apply equally to the disabled persons along with those who are not disabled. All these acts prohibit marriage of a PWD by declaring the marriage null and void if either party is an idiot or lunatic, and where one party is unable to give a valid consent due to unsoundness of mind or is suffering from mental disorder of such kind and extent as to be unfit for marriage or for procreation of children. Further, the rights and duties of the parties to a marriage whether in respect of disabled or non-disabled persons are governed by the specific provisions contained in the Hindu Marriage Act, 1955 (for Hindus) the Christian Marriage Act, 1872 (for Christians) the Parsi Marriage and Divorce Act, 1935 (for Parsis). The Special Marriage Act, 1954 (for spouses of differing religions) the Foreign Marriage Act, 1959 (for marriage outside India). These laws also provide for grounds on which there can be a divorce between the parties among which there is reference to sufferance from incurable leprosy, venereal form of communicable disease, of being mentally unsound or having mental disorders.

PWD Act makes no mention of marriage and parenthood. UNCRPD in Article 23 mandates States Parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, and to ensure that the right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized.

In contravention to the statutory and judicial framework governing marriages, the Central and State governments have implemented various marriage incentive schemes to promote marriages with PWD as a means to improve the social integration of this vulnerable group into mainstream society. There is a range of Central and State schemes whereby monetary support is provided to enable the marriages of PWD. For ex. Odisha and Andhra Pradesh government give a sum of Rs.50,000/-as cash incentive award to either of the spouse if a normal person marries a persons with disabilities. In Kerala marriage assistance is given to daughters of PWD.

Many PWD in the state enjoy the experience of marriage and family life. However, because of stigma and discrimination, lack of access to information and services, especially those on sexual and reproductive health, many do not marry and have children. The myth that PWD will always give birth to children with disabilities stems from a lack of knowledge. Genetic disabilities occur in only a small number of births and can occur even if parents do not have disabilities. PWD should be provided access to information and counselling on the effects of pregnancy and childbirth on their bodies, appropriate medical care during pregnancy and delivery, care for the child, genetic heredity issues and mental well-being. Policies are necessary to ensure that persons with disabilities have access to sexual and reproductive health information and services, including family planning and maternal health.

It was found that only 36.5% had life partners (Table-72). All the rest (63.5%) lived a solitary life. They comprised single, divorcee, separated and widow/widower (Table-73). Disability category wise visually impaired were the ones with spouses followed by those with mobility impairment. There were minimum marriages in the deaf community, and as expected, of the mentally challenged. An interesting finding was there were no separation or divorce among the VI group. There was separation and divorce among all other categories. During conversations with the field researchers it was discovered that most cases of separation was actually desertion of women with disabilities after marriage. The other important finding was there were few divorces which is an indicator of the helpless situation of WWD.

Table 72: Life partner

Willingness for marriage	Single	Married	Total	% without Life Partner	% with Life Partner
In seeing	579	576	1155	50	50
In hearing	400	85	485	82.5	17.5
In movement	900	595	1495	60	40
Mental retardation	328	54	382	86	14
Mental illness	146	57	203	72	28
Any other ***	121	11	132	92	8
Total	2474	1378	3852	64	36

Table 73: Marital status* (N=3852)

Willingness for marriage	Unmarried	Married	Separated **	Divorced	Widow/ Widiwer	Total
In seeing	564	576			15	1155
In hearing	298	85	101		1	485
In movement	630	595	248	14	8	1495
Mental retardation	92	54	228	4	4	382
Mental illness	61	57	54	31		203
Any other ***	121	11				132
Total	1766	1378	631	49	28	3852

* Children excluded

** Deserted after marriage

*** Multiple disability/Autism/Dwarf/Severe Burn/Old age disability/Bed ridden/hunch back

Traustadottir (1990) has mentioned 'Many women may not see marriage as a preferred status, nor may they regard the most traditional female roles as desirable. At the same time, non-disabled women are more likely than women with disabilities to have the possibilities to choose between traditional and nontraditional life-styles. Women with disabilities rarely have the same options and their access to even the most traditional female roles is very restricted.'

In this study, 78.2% expressed the willingness to marry (Table-74). Of the 21.8% who had no desire to marry comprised mostly of women. Perhaps years of subjugation and isolation has created a reticence to lead a normal life. This is corroborated in the findings of several researches

(Deegan and Brooks, 1985; Fine and Asch, 1988; Morris, 1989, 1991; Lonsdale, 1990; Begum, 1992) that most women with disabilities consider marriage to be a significant challenge in the course of their lives. Barker & Maralani (1997) states 'Disabled women are mostly single parents or divorced as compared to disabled men. Also more likely to have a partner or spouse who is disabled.' Wates (1997) writes ' disabled women have sex lives, but most people would never realize it. The nearly total invisibility of the sexual lives of disabled women creates the mis impression that sexuality is not on their radar that sexuality is not an appropriate topic of discussion for them.'

Various, conflicting myths with respect to sexuality and disability prevail in society which perpetuate and reinforce the marginalisation and discrimination of persons with disabilities and create an aversion and fear for marriage among PWD. Examples of some myths include:

- All disabled people are asexual or hyper sexual.
- Intellectually disabled people are incapable of understanding sexuality.
- Physically disabled people are unable to have sex.
- Disabled people cannot/should not be parents.
- Disabled people should be grateful for any type of sexual relationship.

Table 74 : Willingness for marriage

Willingness for marriage	Unmarried	Desire to Marry	%
In seeing	564	483	85.6
In hearing	298	222	74.5
In movement	630	521	82.7
Mental retardation	92	65	70.7
Mental illness	61	29	47.5
Any other ***	121	61	50.4
Total	1766	1381	78.2

2.10.2 Parenthood

There are only scattered accounts of motherhood as experienced by women with disabilities. These accounts have mostly been written by women who have physical disabilities (Anderson, 1985; Hyler, 1985; LeMaistre, 1985) or based on interviews with this

group of mothers (Shaul, Dowling, & Laden, 1985). Mothers with mental retardation have not been represented in this literature, and as a result these mothers are even more invisible than other mothers with disabilities and very little is known about their lives and struggles

Wates (1997), a disabled parent researcher in the United Kingdom, articulates a common challenge to parenthood : 'Disability is so closely associated with dependence and social isolation that it is hard for people to imagine a disabled individual at the centre of family life in the role of primary carer....' 'These exclusions are unconscious; all the same they convey to disabled people that their presence is not expected in the domain of pregnancy, birth and parenthood. When I told people I was researching the subject of disabled parents I noticed that people often thought I was talking about parents of disabled children.' However, other disabled parents appreciate the incredible gift that their children are to them. Of the many positives that mother with disabilities can bring, the ability to celebrate the difference of children, unlike perhaps non-disabled parents who see disability as a load or burden (O'Toole et al). Likewise mothers with disabilities are continually finding ways around problems, to adapt equipment and other technology to achieve their goals (Reid et al 2003), an attribute that shows determination and strength of character.

PWD Act makes no mention of marriage and parenthood. UNCRPD in Article 23 mandates States Parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others and ensure rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; and also to retain their fertility on an equal basis with others.

As a prevention against marriage laws in some countries UNCRPD states that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

Parents with physical disabilities have an average of 2.2 children of whom 27% are children with disabilities. Parents with disabilities are more likely to have adopted children with disabilities (41%) than to birth them (23%) (Barker & Maralani 1997).

In the present study only 47% expressed the desire for parenthood (Table-75).

Table 75 : Desire for parenthood

Disability Category	%
In seeing	31
In speech and hearing	11
In movement	44.2
Mental retardation	36
Mental illness	17
Any other	34
Total	47

Box 20**Voices on marriage and parenthood***

1. *Marriage is not an issue for autistic adults because they live in their own little world- some of them don't even realize there are other people out there and thus marriage is not a necessity here.*
2. *Some autistic people marry and live a happy life. Those who are 'HFA' (High Functioning Autistic) or AS (Asperger Syndrome) often have genius IQ's and are excellent communicators. Social interaction can be a problem but not necessarily.*
3. *The autistic partner may be happy but his wife may be miserable and seriously contemplating dissolving the unhappy so-called union.*
4. *Those who have mild CP lead a happy married life.*
5. *Some CP persons tend to have severe muscle cramping and spasms during intercourse, and so it can be more painful than pleasurable in many cases. This does not go for all cerebral palsied persons, as there are many men and women with cerebral palsy who are married and have children.*
6. *We want to marry but our parents suppress us (OH Woman)*
7. *Life is so complicated, I do not want to add more problems (Deaf woman)*
8. *I have a wonderful in-laws, husband and am very happy with my two children (OH Woman)*

* FGD with young adults and State Consultation 21 March 2012

Recommendations

1. Awareness campaigns need to be planned to break the myth that persons with disabilities will always give birth to children with disabilities; genetic disabilities occur in only a small number of births and can occur even if parents do not have disabilities; and to allay the fear of parents who have children with disabilities.
2. Laws need modification to solemnize marriages of PWDs by providing that a marriage shall not be void or voidable solely because one or both of the spouses were people with disabilities at the time of the marriage.
3. Modification to laws are needed so that 'neither party to a marriage shall be granted a decree of divorce based solely on the ground that the other party is a person with disability.'
4. Persons with disabilities should be able to access information and counseling on the effects of pregnancy and childbirth on their bodies, appropriate medical care during pregnancy and delivery, care for the child, genetic heredity issues and mental well-being.
5. Policies are necessary to ensure that persons with disabilities have access to marriage laws, sexual and reproductive health information and services, including family planning and maternal health.

Voices

"Some men consider a disabled woman an object of embarrassment and they could never think of marrying her. Other men believe that a disabled woman cannot assume full responsibility for the household and for bringing up children. I am lucky that my husband accepted me with full knowledge of my disability and we are happily married with a son and daughter."

Gouri, Upper Limb Amputee, Counsellor ASK, Bhubaneswar.

If the society will support in terms of personal and social security then the parents could think about their children's marriage. We fear for their life. What I they will take away all her money and property and then desert / kill her?"

Soubhagini Sahoo, Mother of MR daughter, Rourkela.



Joshi Deaf Couple with Non-Disabled Daughter, Bhubaneswar



Non-Disabled Woman with One HI and Two Non Disabled Children, Bargarh



Our scope survey, in UK, found nine out of 10 people in Britain have never had a disabled person in their house for a social occasion. Disabled people are "invisible in day-to-day life.

*UK Charity's Chief Executive
Richard Hawke (2010)*



2.11 Social Life and Leisure

Scope survey (Coughlan, 2010) in UK found nine out of 10 people in Britain have never had a disabled person in their house for a social occasion. While the survey found widespread backing for equal opportunities, in practice few people have any personal dealings with people with disabilities. The charity's chief executive, Richard Hawkes, says disabled people are 'invisible in day-to-day life'.

The subject field of leisure studies has developed a close association with social policy research and wider concerns of inequality in society (Kay, 2000). Coalter (1997), for example, has referred to the way in which leisure studies has developed a 'society in leisure' approach with a focus on the ways in which inequalities in society are reflected in leisure (Coalter, 1997). Research has highlighted the interplay between material and cultural forms of exclusion and the ways in which the material and cultural intersect and interact to form a kind of social-cultural nexus of exclusionary practices and discourses in leisure, sport and tourism for persons with disabilities (Aitchison, 2003a, 2005a, 2005b, 2009). The marginalization of disability from the leisure studies research agenda is, however, anomalous with the growing concern with inequity and social exclusion voiced by leisure scholars from the 1970s (Cara, 2009). This growing concern about the exclusion of disability has been acknowledged within sport and physical activity research, although less so within leisure studies research (Cara, 2009).

2.11.1 Social Life and Exclusion

In a community, happy and sad events play important roles in the social lives of the people (Simister and Yunis 1999). 'Happy' events may include marriage, births and successful recovery from surgery, illness or accidents. 'Sad' occasions may include funerals, illness and injury. Exchanging visits with family, relatives, friends and neighbors is the main social activity for people, especially those living in rural areas (Simister and Yunis 1999). Traditional leisure activities within the community include visiting, eating, drinking (tea or coffee), playing cards and talking. Typically, persons with disabilities have had limited opportunities to socialize, which only serves to exclude them from pursuing social and leisure activities that most people enjoy. The chance to socialize has also been limited by conservative attitudes and poor or rigid transport services that link into the wider community.

PWD Act does not speak about social inclusion and leisure. There is only one reference in the chapter on definitions in clause. Clause though not directly, refers to social inclusion.

Box 21**Chapter I - Preliminary (PWD Act 1995)**

- m. *"Institution for persons with disabilities" means an institution for the reception. Care, protection, education, training, rehabilitation or any other service of persons with disabilities;*
- w. *"Rehabilitation" refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric or social functional levels;*

Exclusion is conceptualized through different social processes and dimensions of everyday life: economical, cultural, physical or mental disability, geographical (spatial), political and institutional. In other words, social exclusion is the outcome of a complex process. This study tries to explain social exclusion in the framework of isolation in the family, in interaction with neighbors and relatives.

Isolation in the family level is loud and visible (Table-76). 41.2% were not involved in the house chores. 18.4% were assigned household cleaning and 6.9% washing of clothes. Only 1.2% were allowed to interact and serve guests and relatives. This is a blatant example of assigning PWD to menial works and their isolation.

Table 76 : Domestic chores assigned (N=3496)*

Chores	Number	%
Shopping	404	11.6
Gardening	321	9.2
Cooking	282	8.1
Household cleaning	642	18.4
Washing clothes	241	6.9
Daily worship rituals	123	3.5
Guest hospitality	42	1.2
Nothing	1441	41.2
Total	3496	100

* Children, elderly and severely disabled were not included.

In India, and in Odisha, there is a broader general awareness amongst people of all ages and regions of the importance of a sit-down family meal. In Odisha, food is important people try to have all meals together as a family. The family tends to bond over food. Dining together is also the time when families sit together after a long day and have long conversations. It helps a lot in making the bond stronger in the family.

PWD often are not part of the family dining. They often eat alone. The study found only 52.3% with access to dining (Table-77 and 78). This is not surprising as a similar situation exists for women and girls. Women and girls in India often eat whatever is left over after husbands and sons have eaten. When the query was extended to categories of disabilities, as expected, mentally retarded and mentally ill were among the least included in family dining (2.2% and 1.1% respectively).

Table 77 : Access to Family Dining (N=4103)*

Response	Number	%
Access to family dining	2144	52.3

* Severely disabled excluded

Table 78 : Access to family dining disability wise

Disability Category	Number	%
In seeing	761	35.5
In speech & hearing	335	15.6
In movement	966	45.1
Mental retardation	48	2.2
Mental illness	23	1.1
Any other	11	0.5
Total	2144	100.0

To what extent the risk of social isolation materializes depends on a number of factors (Ivanov, 2011). One of them is where a person with a disability lives. According to data from Europe and CIS, if he or she happens to live in rural area, the risk of social exclusion is most severe. The risk falls by almost half in urban centers, and further in capital cities (Ivanov, 2011). When compared between relatives and neighbors, PWD expressed greater affection and bonding with relatives as compared to neighbors (Table-79 and 80).

Table 79 : Experience with neighbors

Experience with relative	Number	%
Good	2097	50.5
Not so good	1432	34.5
Bad	585	14.1
No response	38	0.9
Total	4152	100

Table 80 : Experience with relatives

Experience with relative	Number	%
Good	3211	77.3
Not so good	644	15.5
Bad	152	3.7
No response	145	3.5
Total	4152	100

2.11.2 Leisure

In every culture, there are hours in the day when people are not formally required to be in school or engaged in household or paid work. They choose to be involved in various activities, and there are public and private programs, organizations and individuals who support their participation. These hours, these activities and often even these programs are considered discretionary (Larson & Verma, 1999). They are viewed as optional - nice but not necessary, or even particularly important. These are the hours, the activities and the programs whose absence or disappearance are noticed by policy makers but decides the quality of life of the individual (Larson & Verma, 1999).

But leisure is an important aspect of everyday life (Henderson & Shaw, 2006) which defines quality of life in present day context Yoshitaka (2006). Inclusion of PWD in mainstream life, though not fully achieved, is perceptible in pursuit of leisure through spiritual practices, sports, yoga and meditation by PWDs. Modern Indian society still respects and encourages ancient practices of meditation and yoga through which the mind and body search for

balance and purity. In response to a specific question on activities they would like to pursue in future, pursuing a hobby, yoga and few others came up as most desired (Technopak 2008). Public recognition of importance of leisure is low, a fact reflected in the scarcity of relevant data.

UNCRPD has a very detailed view on cultural life, leisure and sports. Article 30 deals with participation in cultural life, recreation, leisure and sport. UNCRPD (2009) mandates that States Parties should recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities.

Among leisure activities, the favorite past time among Indians is watching TV. It is ranked as the most popular leisure for 90% of Indians (Technopak Advisors, 2008). Approximately half of all Indian households own a television (Bajaj, 2007). According to Pioneer Investcorp, the Indian cable industry is worth ₹270 billion (US\$ 5.94 billion) and is the third largest in the world after China and the US. The number of TV homes in India grew from 120 million in 2007 to 148 million in 2011. TV viewing is ingrained in the daily routines of individuals (40% of their time), there is perhaps a little thought that lingers across some Indians on the 'usefulness' of the time spent watching television; especially since bulk of the TV viewing time is spent on soaps, film-based programs (Technopak Advisors, 2008). In this context only 30.9% of PWD watch TV in the state (Table-81).

Table 81: TV Watching

Count	%
1285	30.9

The Indian fairs and festivals are a fantastic statement on the country's diversity and multi-cultural character. Same is the situation in Odisha. Odias never miss the opportunity to celebrate festivals and fairs and festivals are awaited events over the year. Rituals, worship and other religious activities are very prominent in an individual's daily life; this is evident from the fact that close to 7 out of 10 individuals consider 'visits to temples / places of worship' as an activity that they would pursue in their leisure time (Technopak 2008). 60% have also engaged in the activity as part of their leisure repertoire, in the last one year (Technospeak 2008). Interestingly, this is also an activity that does not seem to be on the

wane; it is in the consideration set of leisure activities for nearly as many younger people as it is among the older age group (Technopak 2008). In religious rituals persons with disabilities participate with equal respect. For ex. In Makar Sankranti (Singh 2007), all members of the family jointly fly kites as per their capabilities. The elderly and disabled take on the easier task of holding the thread whereas the vigorous task of running and flying is done by children and youth (Preiser & Ostroff 2001). However only 45.4% PWD visit fairs and festivals (Table-82).

Table 82 : Visit to Fairs & Festivals

Number	%
1885	45.4

The popularity of shopping as a leisure can be measured by the statistics of India Microfinance (2009), which states 720 million Indians have joined consuming age by 2010, 55% of the Indian population will be under 20 years of age by 2015, 10% annual growth in Retail market since 2000, 5.5 retail outlets per 1000 population, highest in the world; and there is 25-30% annual growth in retail loans and credit cards. Only 42.1% PWD go shopping (Table-83).

Table 83 : Shopping

Number	%
1750	42.1

Sports are another integral component of leisure. The power of sport as a means to improve the lives of persons with disabilities is reflected in a range of international agreements, strategies and instruments. As early as 1978, UNESCO (1978) identified the value of sport for persons with disabilities in its International Charter of Physical Education and Sport. In 1993, the United Nations adopted The Standard Rules for the Equalization of Opportunities for Persons with Disabilities (1993), which also addressed the right to sport for persons with disabilities. The UN Convention on the Rights of Persons with Disabilities is the first legally binding international instrument to address the rights of persons with disabilities with regard to sport through Article 30 (2009). In colleges only 1.7% students participate in sports and 2.9% in cultural activities (Table-84 and 85).

Table 84 : Participation insports

Responses	Count	%
Yes	10	1.7
No	550	94.0
No response	25	4.3
Total	585	100.0

Table 85 : Participation in cultural activities

Responses	Number	%
Yes	17	2.9
No	537	91.8
No response	31	5.3
Total	585	100

Recommendations

1. All educational institutions, government and private, must provide for disability and age appropriate opportunities for children/youth with disabilities to participate in sports and have access to playgrounds along with other children; and have access to cultural materials in an accessible format and access to cultural activities, performance and services along with other students.
2. Marketplaces must be accessible. Shopping malls and big stores should have both services and personnel to attend customers with disabilities.
3. Local accessible transport in the form of few accessible autorickshaws, taxi services and buses must ply in every township to begin with.

Voices

We are facing problem in various ways for example if we want to go for marketing then one question coming to our mind is that is the shop/mall, roads accessible for the wheel chair? When I went to Kalamandir shop, the staff told my father to get permission of secretary for wheel chair to go inside. Would papa carry me to take inside? I was very hurt and we came back.

Sonali Harichandan, CP, Receptionist, Bhubaneswar

As a deaf person, I face difficulty in accessing information as most of the media, especially television, do not have interpretation services in their programmes – including subtitles.

Mr. Niranjan Joshi, HI, Bank Employee, Bhubaneswar

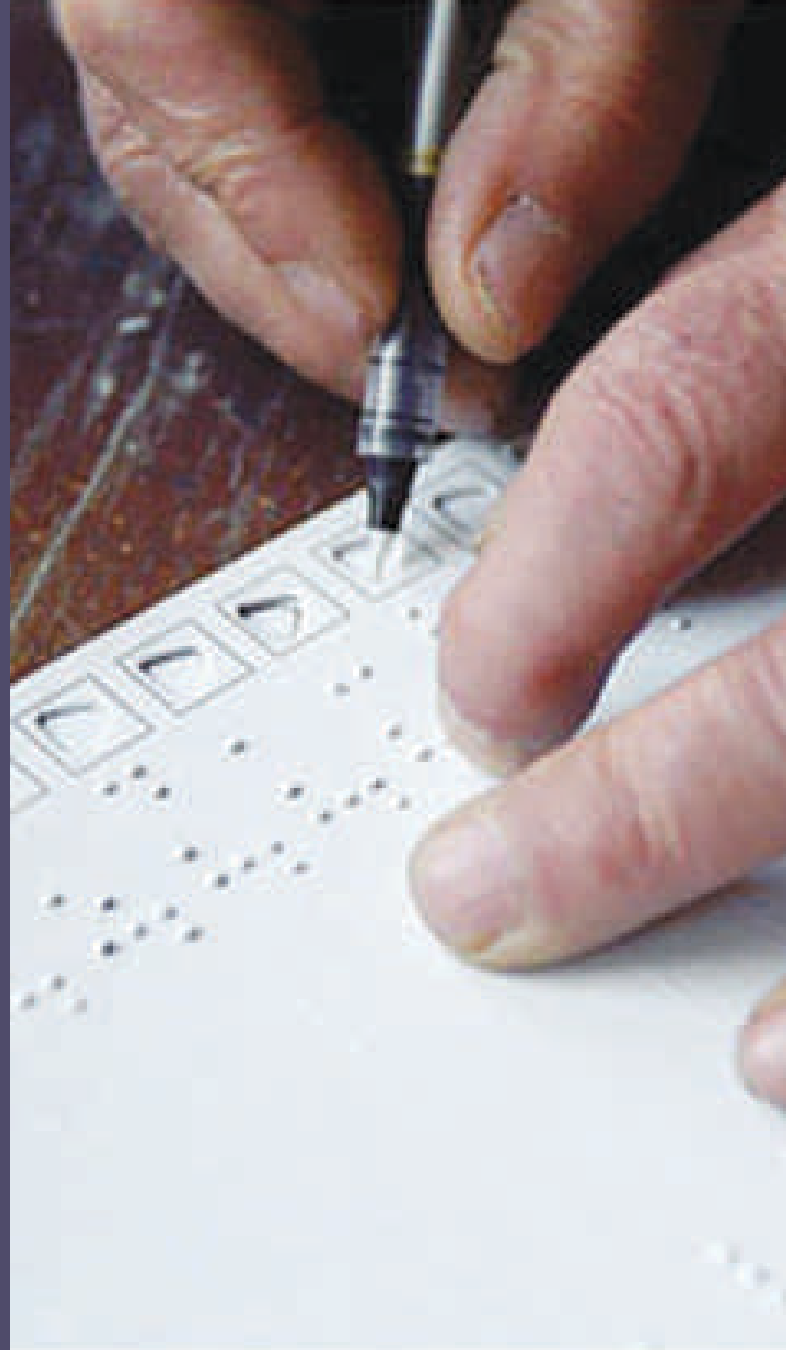
Government should support dancers with disabilities by providing them travel grants and teaching fellowships to participate in national dance festivals and start their own schools.

Shakti Swaroopa Bir, HI, Odissi Dancer



Persons with disabilities are often prevented from exercising this right because of discriminatory laws, the lack of accessible voting booths or because electoral material and information is not available in accessible formats such as sign language and Braille.

Navanetham Pillay
UN High Commissioner for Human Rights, UN New York, 3 Dec 2012



2.12 Political Participation

David Blunkett, while Home Secretary (UK), placed his approach to citizenship within the civic republican tradition of Aristotle's polis, where political participation was the means by which the citizen role was fully expressed (Blunkett, 2003a & b). Disabled people's perspective has been singularly absent from contemporary debates on political participation and citizenship, not just in Britain but also in other democracies (Meekosha and Dowse, 1997). The very language of the debate often excludes people who have physical and/or sensory impairment, mental health problems or learning disabilities. Even feminist challenges to the dominant concepts of citizenship have, in inserting the private world of the family and women's caring role, still treated disabled people as absent (Sevenhuijsen 1997, Lister 1998).

In many countries persons with disabilities are denied the right to vote and stand for election. The right to vote restricted from people without full legal capacity, yet the vast majority of people including those without verbal communication, can express an opinion with adequate support. Political disenfranchisement further increases the political invisibility of people with disabilities and their needs and concerns, and makes it easy for policy-makers to ignore their demands. In advocating for political participation we expose and challenge deeply-held stereotypes and prejudices that people with disabilities are incompetent and easily manipulated, that a rational vote exists (and people with psycho-social disabilities and irrational do not vote rationally), and that giving people with mental health issues the right to vote constitutes a threat to democracy.

In addition to voting every few years, political participation means the receptivity of governmental bodies to reach out and involve people with disabilities in policy-making. The CRPD is essentially an NGO text and was crafted with unprecedented civil society engagement. Willingness for people with disabilities to engage is hardly reflected in domestic legislative and policy reform. Particularly excluded are people with intellectual disabilities, and people with psycho-social disabilities (in Hungary for example, the law excludes psycho-social disabilities from the legal definition of disability).

In India NGOs by organizing mass protests and rallies have been able to bring about some changes. Supreme Court had delivered its landmark judgment that elections be made disabled friendly. Yet facilities for disabled voters, where they did exist, during elections over last two years, were more the exception than the norm. State Election Commissioners are sluggish in implementing disabled-friendly provisions. NGOs and DPOs in India/Odisha have conducted non-partisan state (nation) wide campaign to safeguard and promote the voting rights of people with disabilities.

Box 22

First Political Convention

The Telegraph

Cry for poll equality

Our Correspondent

Bhubaneswar, March 29: People with disability in Orissa are demanding that politicians should take them into account while seeking votes. With elections to the Lok Sabha and the Assembly nearing, the people with disability are demanding that ramps be built in polling booths in Orissa to make them more accessible to wheelchair-bound voters. Among the 40 lakh disabled people in Orissa, at least six lakh have their name enlisted in voters' lists.

At a political convention earlier this month, hundreds of people with disability in Orissa had demanded three per cent reservation for them in the Lok Sabha and Assembly

constituencies of the state. At the convention attended by leaders of the Biju Janata Dal, BJP, Congress, Samajwadi Party and the CPM, the disabled people demanded that they should also get the benefit of reservations that are given to those from the scheduled castes and tribes.

"Arrangements should be made for postal ballots for those under rehabilitation," said Shruti Mohapatra, convener of the Orissa State Disability Network, which organised the convention. For blind voters there should be a trusted escort to guide him or her to the voting machine, the convention demanded.

Though the political class, including BJP, BJD and the Congress, have rejected the demand for reservation in Lok Sabha and Assembly seats for the disabled people, all have supported the demand for a disability commissioner in the state. President of the Orissa unit of the Samajwadi Party, Baishnab Parida, said his party had already included some of the demands put forth by the

Orissa State Disability Network in its election manifesto. The other demands made by the disabled people are 100 per cent medical certification in the state by the end of 2005, Record of Rights for colonies of persons who have been cured from leprosy and disability pension for people with disability below poverty level.

The organisation has asked the chief electoral officer to make electronic voting machines friendly for voters with visual disability.

Box 23

PWDs and Elections

THE TIMES OF INDIA

Disabled Harassed

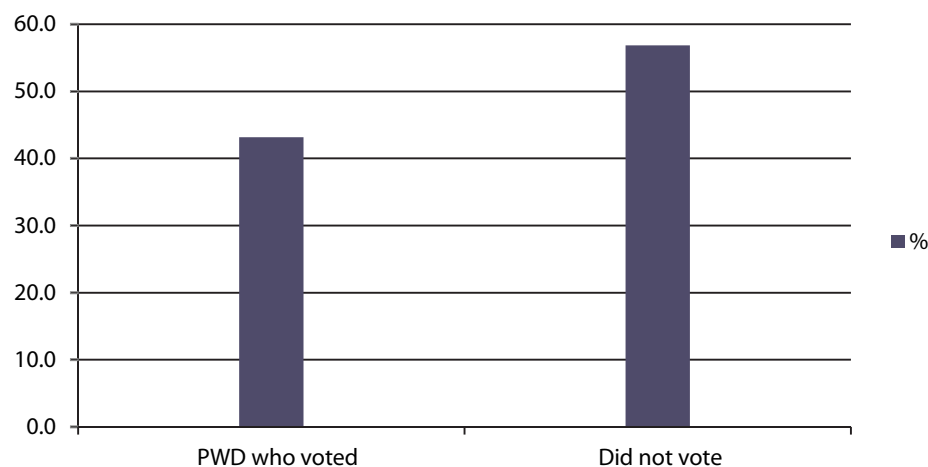
Despite the fact that in 1995 disabled people were guaranteed equal opportunities with the passing of the Disability Act, the situation for the 14th Lok Sabha elections had not changed in 2004 because PWD Act, unfortunately, does not speak about civil and political rights of persons with disabilities. Till 2004 disabled citizens have had to depend on others to cast their vote; persons with visual disabilities could not even keep their choice a secret as they had to take the help of others in casting their vote. Physically disabled people had to be carried into the booth.

WWD were further disadvantaged. Although staff in the polling booth were helpful and courteous, there were no women among them and thus many returned without voting. It uncomfortable being carried in by men and having people stared at. In an unprecedented show of strength, India's disabled people came out of their shell on March 20 and demanded their share of attention from political parties by, for starters, including their needs in election manifestos. The landmark event was a 'National Convention on political rights of disabled people' in New Delhi,

convened by the Disabled Rights Group and 'State Convention' at Orissa convened by Swabhiman. People came together, had an interface with political parties and submitted their Charter of Demands to the major Political Parties.

UNCRPD in Article 29, participation in political and public life, mandates States Parties to guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others. It elaborates ensuring persons with disabilities can effectively and fully participate in political and public life on an equal basis with others by enabling voting procedures, facilities and materials are appropriate, accessible and easy to understand and use; and protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate.

Odisha recorded more than 66% polling in 2004 (ET, Oct 7, 2002) and voter turnout was pegged at 65.9 % in 2009 (Indo Asian News Service, April 17, 2009). In this scenario the population with disability voted abysmally low with only 43.2% casting their vote (Graph-27). Our sample size was 3296. We did not ask questions in this section to children or the severely disabled.



Graph 27 : PWD who voted in 2009 assembly elections

56.8% did not vote (Box-23 & 24). Many factors contribute to this – inaccessible polling booths, lack of signages and Braille-enabled EVMs, personnel not sensitised to the special needs of the disabled and all this despite be courteous to Supreme Court order of 2007 to make things better by demanding that necessary steps be taken to make the polling process accessible to the disabled.

Box 24

PWD could not vote



10 lakh physically challenged could not vote'

Staff Reporter

BERHAMPUR: The physically challenged persons of the Orissa demanded that the Election Commission make special arrangements for them during coming elections. The members of the Ganjam District Orthopaedically Handicapped Welfare Association alleged that around 10 lakh disabled persons in Orissa failed to cast their votes in the recently concluded elections due to lack of facilities like ramps and Braille language enabled electronic voting machines (EVMs).

Leader of the association, K. Anand said although the Supreme Court had directed to provide ramps to enable handicapped persons in wheelchairs to go and vote in polling booths and to have EVMs with Braille language, no where in Orissa such facility was provided except in state capital Bhubaneswar. Mr Anand, who is physically challenged, alleged that a polling official even proposed to vote for him, which he did not agree to.

He doubted whether physically challenged

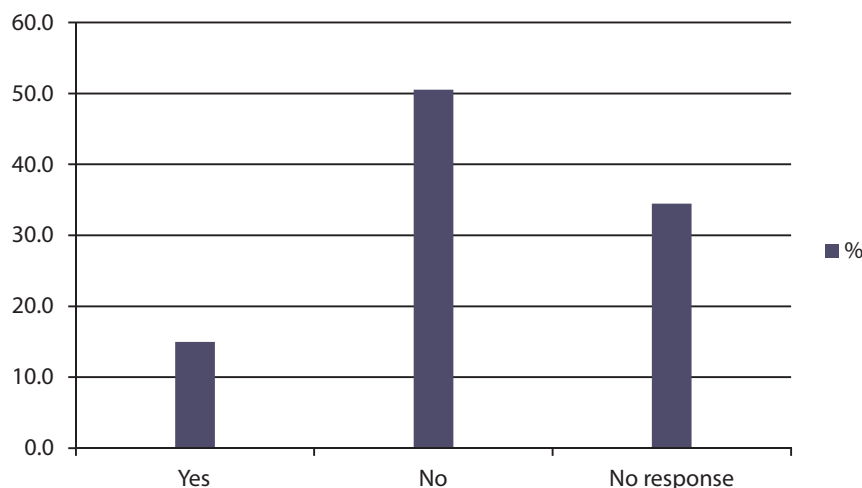
persons like him had got chance to vote freely and independently. The organization also demanded that through proper amendments in the constitution representatives of the physically challenged persons have to be nominated to the parliament as they constituted more than ten percent of the total population.

Court directive

Of those who cast their vote 38.2% did because they did not need any special arrangements. 23.8% pointed towards presence of ramps and ground floor accessible booths as their motivating factor, 23.5% were enabled by cooperative and sensitive officers in polling stations and 14.5% got help from political parties to reach polling booth, get their voters card etc (Table-86). There was clear indication that PWD want their political representatives to be empathetic to their issues. Only 15% said their political representatives were empathetic. 50.6% said a clear no and 34.5% made no comments (Graph-28).

Table 86 : Special arrangements for PWD

Type of health facility from	Number	%
Provision of ramp / ground floor polling	390	23.8
Provision of Braille ballot	0	0
Officials are cooperative	385	23.5
Political party helped	238	14.5
Did not need special support	478	38.2

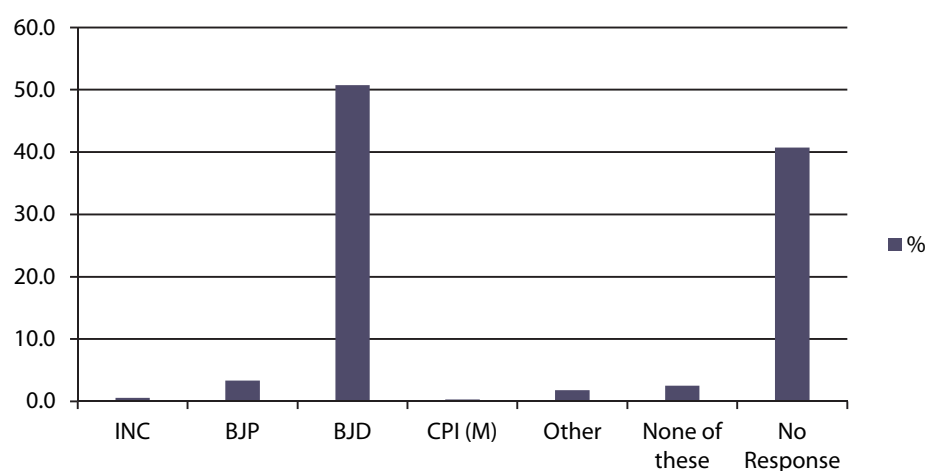


Graph 28 : Empathy of elected representative

The study found a clear reflection of apathy towards political involvement, awareness and interest among PWDs. This is because political parties very rarely contact PWD and while PWD are less likely to view the political system as responsive to 'people like me,' they are as likely as people without disabilities to follow government and public affairs most of the time, and their lower voter turnout is not explained by their perceptions of the political system or their perceived ability to participate. Here in lies a huge vote bank. Political parties and leaders must address this chunk of population. Only 50.7% could say BJD is the ruling party in Odisha. 0.6% said it was INC, 3.3% said BJP, 0.3% said CPI (M) and 2.5% said none of these. What was striking was the lack of response from 40.7% of the respondents (Table-87).

Table 87 : Awareness of PWD about ruling party in Odisha

Rulling Political Party	Number	%
INC	21	0.6
BJP	127	3.3
BJD	1926	50.7
CPI (M)	12	0.3
Other	68	1.8
None of these	96	2.5
No Response	1546	40.7



Graph 29 : Empathy of Political Parties

Only 59.7% could identify Navin Patnaik as the chief minister of Orissa. 1.4% said Biju Patnaik, 0.4% Sonia Gandhi, 1.5% said it was 'other' person and 2.4% said none of these (Table-88).

Table 88 : Knowledge of Chief Minister

Chief Minister of Odisha	Number	%
Navin Patnaik	2265	59.7
Biju Patnaik	54	1.4
Sonia Gandhi	16	0.4
Other	57	1.5
None of these	92	2.4
No response	1312	34.6

When asked about the prime minister of India 535 said Manmohan Singh, 7% said Navin Patnaik, 3.1% said Sonia Gandhi, 2.5% said Pratibha Patil, 12.8% said 'ther' and 31.6% made no response (Table-89).

Table 89 : Knowledge of Prime Minister

Prime Minister of Odisha	Number	%
Sonia Gandhi	119	3.1
Manmohan Singh	2010	53.0
Pratibha Devi Singh Patil	95	2.5
Naveen Patnaik	265	7.0
No	107	2.8
No response	1200	31.6

Recommendations

1. Providing PWDs an equal access to elections by making polling booths and the voting process accessible. Provision of braille ballot and ramps should be mandatory and punishable if not followed.
2. Hearing the voice of PWDs and giving them in elections, by reservation of seats in constituencies, in panchayat to Lok Sabha.
3. Creating wings, such as student wing and women wing, for PWD in political parties.
4. Election posters must be inclusive in their design and print.
5. Provision of accessible political information and communication.
6. Political manifesto to clearly spell the obligations of the party to PWDs; and to be available in accessible format.
7. Modifications of laws which prohibit disabled persons, who are declared legally incapacitated, the right to vote and stand for elections.

Voices

Polling booths are held in high schools in Kharihar. They are in first floor and there are no ramps. I am 50 years of age. I have never voted since my accident.

Pradip Agarwal, OH, President DAN, Nuapada

Availability of braille ballot paper and accessibility to polling booth should be compulsaory in all elections, whether parliamentary, assembly or panchayat.

Lekharam Bhoi, VI, Block Chairman, Balangir

There should be compulsory reservation of seats for PWD in both Loksabha and Rajyasabha in centre and Vidhan Sabha in the state.

Hemant tandi, OH, elected representative, Nabrangpur

Out of 12 nominated MP in Rajya Sabha, by President of India, one mustbe a PWD.

K.Anand rao, OH, Chatrapur, Ganjam

In Panchayat elections, Municipality and Maha Nagar Nigamelections there must be a mandatory prvision for reservation of seats for PWD.

Akshay Kumar Sahoo, VI, Balasore



Virtually every person with a disability encounters human rights violations at some point in their lives and very many experience it every day of their lives.

*Ban Ki Moon
UN Secretary General
3rd December 2011*



2.13 Law, Justice and Grievance Redressal

2.13.1 Laws

The issue of disability directly pertains to the Human Rights. The whole process of Human Rights is a result of devolution of individual. It has been a result of long struggle. Procedural equality is legal. Doctrine of equality, affirmative action is there to ensure that unequal are given facilities to come up like others, to be equal. It is inspired by the principal of greatest happiness of the greatest numbers, Prof. Laski once said "An unequal society lives in a constant fear of disaster. It would be unstable (Spartacus, 2011)."

Justice V.R. Krishna Iyer was the first to speak of disability as a Rights issue in India, in judiciary, and has also written a book titled 'Law, Justice and the Disabled.' In 1973, he was elevated to the Supreme Court and retired from the Bench in November 1980. In his words "An Ombudsman be appointed to redress the grievances of person with disability. The Ombudsman must have the power to give compensation. It must have power to supply limbs (orthotic and prosthetic aids) at the state's expense; and also the power to command hospitals to provide treatment and ensure free medical treatment for persons with disability. It must make Article 14 of the Constitution a reality in a comprehensive sense. In the sense that wherever there is any disability there is inequality and for equal treatment before the law, remedies must be provided to correct the maladies. This will take many forms including hearing, speech, eyesight and other deficiencies. The power to ensure that the state provides facilities for leisure and sports to persons with disability must also be within the jurisdiction of the Ombudsman.'

The Parliament of India passed the Persons with Disabilities Act in 1995. Passing of this Act was a landmark step to make people with disabilities an integral part of the Indian main stream. The Act guarantees full equality, independence and accessibility to all persons with disabilities to the services and facilities needed in day today living. The Act enlists the rights and facilities that a person with disabilities would be entitled to and the responsibilities and obligations which are placed on the Govt. of India, State Govt., local bodies, NGOs and citizens at large.

The Act (Box-26) provides for a Chief Commissioner at the Government of India level and a Commissioner in each State. To provide adequate and speedy redressal to the grievances of disabled persons the CCD has been made a Quasi Judicial authority having powers of a judicial court. Defaulting Governments, organizations, official thus; can be issued court summons, records can be called for to issue suitable directions. He/she has to also supervise working of Disability Commissioners in States. He/she can initiate-Suo moto proceedings.

Box 25**Chapter XII - The chief commissioner and commissioners for persons with disabilities**

57. *(1) The Central Government may, by notification appoint a Chief Commissioner for persons with disabilities for the purposes of this Act.*
58. *The Chief commissioner shall ---*
- (a) Coordinate the work of the Commissioners;*
 - (b) Monitor the utilization of funds disbursed by the Central Government;*
 - (c) Take steps to safeguard the rights and facilities made available to Persons with disabilities;*
 - (d) Submit reports to the Central Government on the implementation of the Act at such intervals as that Government may prescribe.*
59. *Without prejudice to the provisions of section 58 the Chief Commissioner may of his own motion or on the application of any aggrieved person or otherwise look into complaints with respect to matters relating to --*
- (a) Deprivation of rights of persons with Disabilities.*
 - (b) Non-implementation of laws, rules, byelaws, regulations. Executive orders, guidelines or instructions made or issued by the appropriate Governments and the local authorities for the welfare and protection of rights or persons with disabilities. And take up the matter with the appropriate authorities.*
60. *(1) Every State Government may, by notification appoint a Commissioner for persons with disabilities for the purpose of this Act.*
61. *The Commissioner within the State shall-*
- (a) Coordinate with the departments of the State Government for the programmes and schemes, for the benefit of persons with disabilities;*
 - (b) Monitor the utilization of funds disbursed by the State Government;*
 - (c) Take steps to safeguard the rights and facilities made available to persons with disabilities.*
 - (d) Submit reports to the State Government on the implementation of the Act at such intervals as that Government may prescribe and forward a copy thereof to the Chief Commissioner.*
62. *Without prejudice to the provisions of section 61 the Commissioner may of his own motion or on the application of any aggrieved person or otherwise look into complaints with respect to matters relating to---*
- (a) Deprivation of rights of persons with disabilities;*
 - (b) Non-implementation of laws, rules, bye-laws, regulations, executive orders, guidelines or instructions made or issued by the appropriate Governments and the local authorities for the welfare and protection of rights of persons with disabilities, And take up the matter with the appropriate authorities.*

UNCRPD in its Article 13 (Access to justice) mandates States Parties to ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

The Persons with Disabilities Act (PWD) was signed into law make sure that persons with disabilities are protected from discrimination. After a series of Supreme Court and High Court rulings, however, people who are discriminated against because of an intellectual, psychological, or physical impairment often are not able to prove that they are entitled to any protections at all under the PWD Act. The courts so narrowly defined who was a person 'with a disability' under the law, that people with vision in only one eye, significant hearing impairments, severe burn resulting in mobility, and other conditions don't have protection from discrimination. Despite this Sushanta Dakua filed a case of discrimination against NALCO in Odisha High Court. He showed up for his court date to discover that there were no sign language interpreters to help him present his case.

During the state level consultation (organized by Swabhiman) on 21st March 2012, held at OAB Conference Hall, PWD opined that starting a court case in India is a tiring and time-consuming business. The legal and judicial system frightens most people in India. If non-disabled people wince at the words 'court case', what would be the reaction of someone who has to contend with disability and indifference; someone who is marginalized and discriminated against?

2.13.2 Justice

Justice is a far cry in India for PWD. None of the courts have ramps; braille transcripts or audio books; or sign language interpreters. Sashanka Sekhar Mishra with 60% disability (OH) was a student of University College of Engineering, Burla (U.C.E, Burla) in B.tech in Information Technology under Biju Pattnaik University of Technology (B.P.U.T), Orissa. In the 1st year itself he was unscientifically notified as year back and his promotion to 2nd year was with-held in the year 2006. In the year 2008 he was again notified as year back and his promotion to 3rd year was withheld but this time under new autonomous rules and regulation of U.C.E, Burla which was unlawful as autonomous rules of U.C.E, Burla are applicable for 2006 batch onwards but he being of 2005 batch was governed by the rules and regulation of B.P.U.T Odisha. Against this illegal decision he moved Honorable High Court (W.P.(c) no 17998/2008). On 20th April 2009 Honorable High Court of Orissa gave its final verdict in favor of him but the college defied the order and did not promote him. He was harassed by all.

2.13.3 Grievance Redressal Mechanism

RTI applications are being regularly violated. Swabhiman has filed RTI applications for information on disability pension recipients, MGNREGA jobs for persons with disabilities, LLC functioning but most remain unanswered.

Court of Disability Commissioner - Their orders are not respected by government departments, mostly juniors are sent to represent the authorities against whom summon is issued and very rarely appearances are made by government authorities. When the State Commissioner for Persons with Disabilities did not acknowledge or respond to our letters an RTI application was filed. Of the 609 cases filed till 2011 December decisions have been taken only on 109. To the question 'how many judgments have been in favor of persons with disabilities', the response was a vague one 'Judgment were on the merit of the each individual case. SCPD being a quasi-judicial body, the cases were decided as per laws prevailing and on the basis of evidence within the provisions of the PWD Act.' During various FGD and State consultation on 21st March 2012 most PWD expressed their discontentment and unhappiness over functioning of present commissioner's office.

2.13.4 Discrimination

Employment - Although few employers today likely would articulate a view that members of certain racial or ethnic minorities are not intelligent enough to hold some jobs, many freely express the view that people with disabilities are not capable of performing, even though this stereotype has been thoroughly refuted by the empirical data. In contrast to race and ethnicity, which are generally recognized to bear no relation to an individual's abilities, the mere fact of having a disability is still believed to convey important information about a person's potential and limitations beyond the particular disability itself. There are many other ways in which it has become harder for people with disabilities to enforce their rights. For example, Government of Odisha notified posts for 'siksha sahayak' in high schools. Unfortunately all the posts reserved for candidates with visual impairments was for science. It is a well known fact that very few candidates with disabilities complete graduation because of several obstacles. And 99% are from humanities background. In such a situation instead of reserving posts in humanities, reserving in science is another way of elimination of the disabled from government jobs. Satyanarayan Mishra – Utkal University had advertised for teaching posts on 22.05.2009, in which there is no reservation for persons with disabilities (PWD). In the advertisement dated 12.06.2006 a post was shown to be reserved for PWDs but when further advertisement was issued by the

University on 22.05.2009 the reservation position was not identified with reference to any post. Under section 33 and 39 of the PWD (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 it is mandatory to reserve 3% of vacancies for PWDs. (In the year 2003 in Utkal University, Post of lecturer in History was reserved for physically handicapped persons, but subsequently it was de-reserved. Again in 2006 when reservation was reintroduced Dr. Satya Narayan Misra had applied for the post of lecturer in History and was qualified and got an appointment on contractual basis with a consolidated remuneration of rupees 10,000/- per month but he did not accept the appointment as it was a contractual.

In 2009 again an advertisement was issued but without reservation for persons with disabilities). The issue here is not whether Dr. Satya Narayan Mishra should or should not get the job. The primary issue is how the University can violate the mandates of PWD Act 1995 and G.A.Department Resolution No.25384 dated 20.09.2005. Despite several letters to all authorities, filing of case in the court of Disability Commissioner, nothing happened. South Eastern Railway - Endless waiting from 2009 to till now, for a group of 44 hearing impaired candidates who had qualified in the written examination then interview and medical test also but after that their appointment has been neglected by the railway recruitment board. On April 13, 2005 ECoR sought applications from physically challenged persons for recruitment in group C and D categories. The written test was conducted after 4 years on March 8 2009 and the result was out on March 23 the same year. The selected candidates still waiting for their posting and the railway board is playing pretty game over the fate of 44 disable candidates. They have written to all authorities with complete apathy from all ends. Sushanta Kumar Dakua – A person with hearing impairment qualified Asst Grade II (sedentary job) examination and interview successfully in NALCO. After my medical examination for joining the job NALCO hospital referred him to Kalinga Hospital for medical fitness test from cardio-vascular point of view. Kalinga hospital certified him medically fit for this particular job from the cardio vascular point of view for this job. Despite that he was handed over a letter saying 'Medically Unfit by NALCO Medical Board.' He ran from pillar to post with succor.

Entitlements (Jagatsingpur) - A group of more than 280 persons with disability are in endless waiting from august 2010 to till date to get assistive device for daily living, like wheel chair, crutch, blind stick for the visually impaired people and hearing aids for the hearing impaired people. Their inquiry at SIDR Bhubaneswar, for the reason of delay, led to a watery excuse that government does not have any budget for this. They knocked at the office of the Commissioner for persons with disability to no avail.

Mass Protest -Apathy continues (2nd March 2012)

'All were so happy, relaxed and some of the member cried in joy after wining.' This was the situation just after the return of a 7 member delegation, after a 45 minutes successful meeting with Chief Secretary of Odisha, on the demand to retain 3% reservation in all contractual appointment of OPEPA. But all the effort of mass protest had gone waste. They discovered this on receiving the proceedings from government which made no mention of reservations in OPEPA contractual post. 'This is the naked truth about our government and the person who are in the chair for the welfare of the disabled.' Said Sannyasi Behera, VI, activist.

Recommendations

1. State Commissioner for Persons with Disabilities shall be a persons with disability; or if such person is not available then parent of a special child.
2. As it is difficult for PWD to reach the courts, mobile courts should be set up which can reach PWD.
3. For justice to reach the most needy, District Disability Commissions must be set up in each district of the State.
4. The District Commission shall consist of two full-time members including a President who is a retired judge of a District Court and a person with disability belonging to a self-advocacy or peer support group or a person having adequate knowledge or experience of, or have shown capacity in dealing with issues of human rights and rights of persons with disabilities.

Voices

Commissioner for PWDs should be a person with disability or a parent.

M.M.Prusty, Father of MR boy, Bhubaneswar

'We are hopeless now by seeing all this drama of SIDR staff we don't have any faith on them and also we are tired of visiting the office of disability commissioner to get our basic need as persons with disability.'

Kalyani Khatua, OH, Jagatsinghpur

Interviews of Leaders in Disability sector in Odisha (Interviewer – Asit Ku. Behera)**Sruti Mohapatra, OH**

- *What do you think has been your biggest contribution so far?*

Making disability visible in government and civil society; the culture of access (ramps) in Odisha; initiating the single window approach in Rourkela which has become a regular government program now; creating a second generation of leaders in disability movement; uniting PWD for greater causes like creation of office of disability commissioner, creation of department of disability affairs are few. The list is long.

- *On the basis of priority (as per you) list the issues surrounding PWDs?*

1. Proper disability evaluation and certification, 2. Disability to be treated as a priority agenda in all government departments, 3. Food, 4. Access, 5. Education, 6. Employment and 7. Health.

- *Why has the disability movement in Odisha not grown as powerful as dalit movements or any other movements?*

There is hardly any coordination among disabled activists. Only blind people are fully organized. And there is no coordination among the various disability networks. Most of the NGOs for disabled people are run by non-disabled people. So it is difficult for them to perceive the trauma of being disabled.

Prafulla Rout, VI**Ex headmaster of BB School for the Blind and present Vice President of NAB**

- *What do you think has been your biggest contribution so far?*

Working for education rehabilitation of poor blind students and giving opportunities to the rural, poor, blind students to realize the dream of education.

- *On the basis of priority (as per you) list the issues surrounding PWDs?*

1. Right to food, 2. Social security and respect for women with disability 3. Educational rehabilitation of the rural blind

- *Why has the disability movement in odisha not grown as powerful as dalit movements or any other movements?*

There is no unity among the different leader or networks those who are working for disability. Most of NGOs are only working for projects not for the cause.

Sannyas Behera, VI, SNAC State Coordinator and Activist

- *What do you think has been your biggest contribution so far?*

Translation of UNCRPD in Odia, preparation of a compendium of government order for PWDs, special railway reservations counter for PWD in Bhubaneswar railway station.

- *On the basis of priority (as per you) list the issues surrounding PWDs?*

1. Accessibility for all in all forms of communication, 2. Brail signage in 2, 5 and 100 rupees coin, 3. Health, education, employment and social security for all PWD

- *Why has the disability movement in Odisha not grown as powerful as dalit movements or any other movements?*

The funding agencies are not funding the disability movement and there is also lack of political will to strengthen the networks.



In mainstreaming disability into international cooperation, networking is a key element. Many DPOs have developed into a global forum for the exchange of experiences by learning and sharing good practices, and global networking.

**Mr. Shuaib Chalklen of
Special Rapporteur
on Disability in UN, February 2012**



2.13 Networking

In Orissa there are three state level active, cross-disability, networks, viz OSDN, OVM and ODPN. A new student's network SUVI (Students Union of Visually Impaired) is emerging. This is apart from OAB, OAD, AOOHWA and NAB which though old are disability specific.

OSDN (Orissa State Disability Network) is the first and oldest network. On 18 of September 2002 SWABHIMAN initiated an annual event, a state level advocacy workshop, to explore how community can create change. Entitled 'People's Perspectives: United Voices For Disability Equity' it focused on persons with disability becoming equal partners in the society. It was a dynamic exploration of how people and the community can address key issues where Ignorance is causing immense harm either way, both to the disabled population and to the state's economy. The objectives of OSDN is to promote local advocacy groups and build leadership in the disability sector, facilitate local advocacy groups to join hands with district level groups to eventually form a umbrella network that would act as a pressure group to influence meaningful policies at various levels – village, block, district state and national, regarding persons with disabilities. It has chapters in all 30 districts. Its major achievements are letter campaigns to Chief Minister's office for Disability Commission (Box-25), establishment of Second Medical Board in Sundergarh District (history in India), single window approach for disability certification at Rourkela and Nuapada, which today has become Orissa Government's regular feature, conducted first political Convention (First In India) in Bhubaneswar. The Census 2011 campaign in the state (Get Yourself counted) was an example of successful networking in reaching remote corners of the state.

OVM (Orissa Vikalang Manch) has chapters in all districts of the state and regularly organizes rallies, protest march and dharanas.

Sannyasi Behera is the state coordinators of ODPN (Orissa Disabled People's Network). ODPN is proactively working on issues of education employment, land rights and entitlements.

Box 26

Strength of Networking

United Voices For Disability Equity (21st February 2010, 9 am to 5 pm, VRC, Bhubaneswar)

A long journey from 1996 to till 2010 in the state of Orissa. On 21st February almost all organizations working in Orissa, across disabilities, across districts and across networks united and demanded an Independent Disability Commission with full time Commissioner. Under the aegis of United Voices for Disability Equality (UVDE), a platform created by Dr. Sruti Mohapatra, disabled people met and demanded filling up of the post before the ensuing Assembly session for immediate redressal of the problems of people with disabilities (PWDs). Committees were formed to meet the

A long journey from 1996 to till 2010 in the state of Orissa. On 21st February almost all organizations working in Orissa, across disabilities, across districts and across networks united and demanded an Independent Disability Commission with full time Commissioner. Under the aegis of United Voices for Disability Equality (UVDE), a platform created by Dr. Sruti Mohapatra, disabled people met and demanded filling up of the post before the ensuing Assembly session for immediate redressal of the problems of people with disabilities (PWDs). Committees were formed to meet the

Table 90 : History of disability movement for formation of state disability commission

Sl. No.	Date or Year and Month	Nature of Activity Dharana/Rally/Post Card Campaign/ Media Advocacy/ Letters to Government	Name of Leader of Activity	Number of People Involved	Outcome
1.	1994	Political Interface	Sri B.K. Parida, OAD	350	Public Sensitization
2.	1997	Rally	Sri M.N. Ray, AOOHWA	200	Memorandum submitted to Government
3.	1997	Letters to Government	Sri M.N. Ray along with OAB & OAD	10	Met CM & he assured of a commission soon
4.	1998	Political Interface	Sri B. Mahala, OAD	200	Public Sensitization
5.	1999	Post Card Campaign &	Mr. Binodbihari Sahu OAB	5000	Public Sensitization
6.	2003	Post Card Campaign	Dr. Sruti Mohapatra OSDN	5000	Pressure on Chief Minister
7.	2004	First Political Convention	Dr. Sruti Mohapatra OSDN	1200	Leaders of all political parties interacted with PWDs.
8.	2004	Question in Assembly	Sri B. Mahala, OAD	150	Public Sensitization
9.	2004	Rally	Dr. Sruti Mohapatra & Late Mr. Ashok Hans OSDN	500	Public Awareness and Memorandum to Governor
10.	2004	Met Political Party Leaders	Dr. Sruti Mohapatra Swabhiman and OSDN	200	BJD & CPI(M) included issues in manifesto

11.	2005	Question in Assembly through MLAs	Sri Sanyasi Behera OAB		Pressure created in legislature
12.	2005	Political Interface	Sri Sanyasi Behera OAB	50	Public Sensitization
13.	2007	15 th National	Sri A.K. Jena President, OSCCPA	50	Awareness Sensitization
14.	2007	Question in Assembly through MLAs	Dr. Sruti Mohapatra OSDN		Discussion in assembly
15.	2008	Conventional Meeting	Sri A.K. Jena President, OSCCPA	20	Submitted memorandum to Secretary(WCD)
16.	2009	Political Interface	Mr. Sanyasi Behera	30	Public Sensitization
17.	2009	Rally & Dharana	Umesh Purohit and K. Anand, OVM	1000	Public Awareness
18.	2009	Rally	Mr. Sanyasi Behera OAB	600	Met the CM & Memorandum Submitted. Assurance.
19.	2010	Meeting	Mr. A.K. Jena OSCCPA	50	Submitted 25 point charter of demand including for commission.
20	2010	Letter to Chief Minister and Governor	Dr. Sruti Mohapatra Swabhimani	1	Pressure on Government
21	2010	Meeting	ODPN	50	Commissioner cum Secretary W & CD Dept. was appraised of the problem.
22	2010	Meeting	Dr. Sruti Mohapatra	10	Decided to bring all organizations and PWD together for commission formation.

Voice

DPOs in Odisha lack in principles and legal capacity. Although there is collective approach to various issues the individuals often supersede the group.

Umesh Purohit, OH, Youth Service Centre, Bolangir





Chapter 1

SWOT Analysis

The table given below presents a SWOT analysis of the current status of the disability sector in Odisha. The major critical impediment to this is the implementation gap characterized by a lack of appreciation of accountable and transparent governance structures, the lack of coordination between line ministries on cross-cutting issues, combined with the paucity of robust statistics in relation to disability. It will indeed be fascinating to see what happens within this sector in the future.

SWOT Analysis of the disability sector in Odisha

Strengths

- India has passed four legislations for the protection of rights of PWDs.
- India has ratified the UN Convention on the Rights of Persons with Disabilities
- Odisha government has prepared rules for PWD Act 1995.
- Odisha government has established office of commissioner for disabilities.

Weaknesses

- Despite progressive legislation there are inadequate implementation modalities
- There is a lack of robust statistical data on disability issues, particularly at district level and below.
- There is a lack of coordination between different departments on cross-cutting issues such as disability.
- The disability movement lacks sufficient organizational capacity to effectively lobby the government.
- There is a lack of collaboration between the disability movement and the concerned departments and officers for PWD.
- Demand for disability services far outstrips supply.
- Persons with disabilities have been excluded from the planning and development process;
- There is currently no social assistance programs for persons with disabilities. The Rs.200 per month, disability pension, is a measly amount to be considered a social assistance. And its reach is very limited.

Opportunities

- The ratification of the UN Convention on the Rights of persons with disabilities provides the Odisha Government with a unique opportunity to take forward a rights-based agenda to disability issues.
- Bilateral and multilateral donor agencies are becoming increasingly aware of the systemic entrenched social inclusion, marginalization and discrimination encountered by persons with disabilities.
- Furthermore, bilateral and multilateral donor agencies are giving priority to assisting the Odisha Government in its quest to reform the public sector and to provide substantial assistance in rebuilding the social, political and environmental infrastructure in Odisha. This has the potential to significantly improve the lives and livelihoods of persons with disabilities.

Threats

- Unless there is a structural public sector reform which address the implementation gap that has been identified then it is unlikely that persons with disabilities will be able to exercise their constitutional rights.
- The severity and extent of social exclusion, marginalization and chronic poverty is so ingrained that it will take decades for this situation to be rectified.
- Without increased commitment and political will to implement a rights based agenda to disability issues, it is unlikely that sufficient human and natural resources will be made available for disability service provision.



Annexure - 1

Suggestions for People First Language

Remember: a disability descriptor is simply a medical diagnosis.

People First Language respectfully puts the person before the disability.

A person with a disability is more like people without disabilities than different.

SAY:

People with disabilities.

He has a cognitive disability / diagnosis.

She has autism (or a diagnosis of...).

He has Down syndrome (or a diagnosis of..).

She has a learning disability (diagnosis).

He has a physical disability (diagnosis).

She's of short stature / she's a little person.

He has a mental health condition / diagnosis

She uses a wheel chair / mobility chair.

He receives special ed services.

She has a developmental delay.

Children without disabilities.

Communicates with her eyes / device / etc

People we serve

Congenital disability

Brain injury

Accessible parking, hotel room etc

INSTEAD OF:

The handicapped or disabled.

He's mentally retarded.

She's autistic

He's Down; a mongoloid.

She's learning disabled.

He's a quadriplegic / is crippled.

She's a dwarf / midget.

He's emotionally disturbed / mentally ill.

She's confined to / is wheelchair bound.

He's in special ed.

She's developmentally delayed.

Normal or healthy kids.

Is non-verbal.

Client, consumer, recipient etc.

Birth defect

Brain damaged

Handicapped parking, hotel room, etc



Annexure - 2

Field Research Team



Akshya Behera
2nd yr MSW, CSSR



Asit Kumar Behera
Swabhiman



Bharati Mohapatra
Ex. Staff, Swabhiman



Bikram Kishore Rana
2nd yr MSW, BPCSW



Brajendra Prusty
2nd yr MSW, CSSR



Chintu Nayak
+3 2nd yr
BJB Auto College



Deepak Ku. Maharana
2nd yr MSW, CSSR



Girija Nadini Swain
1st yr MSW, BPCSW



Jyoti Prasan Patnaik
2nd yr MSW
BJB Auto College



Kurban Khan
1st yr MSW, BPCSW



Lokapriya Kanungo
TISS, Mumbai



Manas Ku. Pradhan
Swabhiman



Rajesh Ranjan Mohanty
Swabhiman



Saroj Karan
1st yr MSW, BPCSW



Sonali Das
1st yr MSW, BPCSW



Soumya Mishra
1st yr MSW, BPCSW

Pravat Ghadei, Saroj Karan, Subhakanta Lenka, Manmohan Das, Susil Mishra of BPCSW

- AIHW 2004. Disability and its relationship to health conditions and other factors. Disability series. AIHW Cat. No. DIS 37. Australian Institute of Health and Welfare.
- Andrey, I. (2011) Social exclusion is higher for PWD as compared with other marginalized groups (An insight into factors affecting social exclusion for people with disabilities).UNDP Regional Human Development Report: Beyond Transition, Towards Inclusive Societies, June 2011.
- Aitchison, C.C. (2003a). Gender and leisure: Social and cultural perspectives. London: Routledge.
- Aitchison, C.C. (2005a). Feminist and gender research in sport and leisure management: Understanding the social-cultural nexus of gender-power relations. *Journal of Sport Management*, 19(4), 222–241.
- Aitchison, C.C. (2005b). Feminist and gender perspectives in tourism studies: The social cultural nexus of critical and cultural theories. *Tourist Studies*, 5(3), 207–224.
- Aitchison, C.C. (2009, February). Changing the culture of tourism research: Challenging the false dichotomy of tourism management and tourism studies. Keynote paper presented at the 18th Annual Conference of the Council for Australian Tourism and Hospitality Education on See change: Tourism and hospitality in a dynamic world, Freemantle, Western Australia.
- Anderson, L. (185). The Lois Anderson story. In S. E. Browne, D. Connors, & N. Stern (Eds.), *With the power of each breath: A disabled women's anthology*. Pittsburgh, PA: Clies Press.
- Antonovsky, A. (1987): *Unraveling the Mystery of Health*, San Francisco: Jossey-Bass.
- Antonovsky, A. (1991): The Structural Sources of Salutogenic Strengths, in C. L. Cooper & R. Payne (Eds.), *Personality and Stress: Individual Differences in the Stress Process* (pp. 67-104). Chichester, UK: Wiley.
- Bajaj, V. (2007). In India, the Golden Age of Television Is Now. *New York Times*, Published: February 11, 2007 (Mumbai, India). Available at <http://www.nytimes.com/2007/02/11/business/yourmoney/11india.html?partner=rssnyt&emc=rss>
- Barker, Linda Toms; Maralani, Vida. (1997) *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities*. Final Report, July 1997. Berkeley: Through the Looking Glass.
- Batra, S. (1981). *Social Integration of the blind: A study in Delhi*, New Delhi, Concept Publishing Company.
- Begum, N. (1992) 'Disabled Women and the Feminist Agenda,' *Feminist Review*, 40, Spring, p.70-84.
- Berthoud, R. (1998), *Disability Benefits: A review of the issues and options for reform*. York: York Publishing Services
- BISWA : <http://www.biswa.org/en/Water-Sanitation>
- Blunkett, D. (2003a). *Civil Renewal: A new agenda*. The CSV Edith Kahn Memorial Lecture. London: Home Office and CSV.
- Blunkett, D. (2003b). *Active Citizens, Strong Communities: Progressing Civil Renewal*, London: Home Office.
- Braithwaite, J. and D. Mont (2008): *Disability and Poverty: A Survey of World Bank Poverty Assessments and Implications*, February 2008.
- Cara, A. (2009): Exclusive discourses: leisure studies and disability, *Leisure Studies*, 28:4, 375-386. Available at <http://dx.doi.org/10.1080/02614360903125096>
- Coalter, F. (1997). Leisure sciences and leisure studies: Different concept, same crisis? *Leisure Sciences*, 19(4), 225–268.

Reference

- Coleridge P. (1993). *Disability, Liberation and Development*. Oxford: Oxfam.
- Coughlan, S. (2010). Disabled are socially excluded says Scope survey. BBC News (31 August 2010 Last updated at 23:03 GMT). Available at <http://www.bbc.co.uk/news/education-11139534>
- Craig, G., Paul, D., Bradshaw, J., Garbutt, R., Sarah, M., Syed, A. and Ward, A. (2003) 'Underwriting Citizenship for Older People: the impact of additional benefit income for older people', Working Papers in Social Sciences and Policy, No. 9, University of Hull.
- Deegan, M. J., & Brooks, N. A. (Eds.) (1985). *Women and disability: The double handicap*. New Brunswick, NJ: Transaction Books
- DFID (2000): *Disability, Poverty and Development*, Department for International Development, London www.dfid.gov.uk
- Durlauf, S. (2001): A Framework for the Study of Individual Behavior and Social Interactions, *Sociological Methodology*, 31: 47-87.
- Dzikus. A. (2008). Access to Water and Sanitation for the Disabled or the Differently Abled. Presentation by Andre Dzikus, Chief, Water, Sanitation and Infrastructure Branch, Section II, and Debashish Bhattacharjee, Human Settlements Officer, Water, Sanitation and Infrastructure Branch, Section II, 22 May 2008, Addis Ababa, Ethiopia
- Elwan, A. (1999) *Poverty and Disability: A Survey of the Literature* World Bank, Washington, USA.
- ET. (2002). Oct 7, 2002 - <http://articles.economictimes.indiatimes.com/keyword/voter-turnout>
- Evans, G. (2004): The environment of childhood poverty. *The American Psychologist*, 59, 2, 77-92. EUROPS. (1998). *The ability to work*.
- Fine, M., & Asch, A. (Eds.). (1988). *Women with disabilities: Essays in psychology, culture, and politics*. Philadelphia, PA: Temple University Press.
- Ganesh KS, Das A, Shashi JS. (2008) Epidemiology of disability in a rural community of Karnataka. *Indian Journal of Public Health*, 2008; 52: 125-129.
- Hawkins, J., Goldstone, C. and Bhagat, M. (2007) *Knowing and understanding Disability and Carers Service customers*, DWP Research Report No. 439.
- Henderson, K. A., & Shaw, S. M. (2006). Leisure and gender: Challenges and opportunities for feminist research. In C. Rojek, S. M. Shaw & A. J. Veal (Eds.), *A handbook of leisure studies* (pp. 216-230). Palgrave Macmillan Ltd
- Hyler, D. (1985). To choose a child. In S. E. Browne, D. Connors, & N. Stern (Eds.), *With the power of each breath: A disabled women's anthology*. Pittsburgh, PA: Clies Press.
- Indo Asian News Service (2009). Orissa voter turnout pegged at 65.9 percent. Friday, April 17, 2009. Available at <http://www.india-forums.com/news/politics/168797-orissa-voter-turnout-pegged-at-65-9-percent.htm>
- India Microfinance. (2009). *India Retail Market Statistics*. Editorial Team, February 4 (2009). Available at <http://indiamicrofinance.com/india-retail-market-statistics.html>
- Indian Council of Medical Research. (2007) *Prevention of Disability in Children*. ICMR Bulletin, 2007; 37: 9-16.
- International Disability Rights Monitor. (2005). *Regional Report of Asia*.
- Ivanov, A. (2011) Social exclusion is higher for PWD as compared with other marginalized groups (An insight into factors affecting social exclusion for people with disabilities). UNDP Regional Human Development Report: *Beyond Transition, Towards Inclusive Societies*, June 2011.

- Kay, T.A. (2000). Leisure, gender and the family: The influence of social policy. *Leisure Studies*, 19(3), 247-265.
- Kobe FH and Mulik JA (1995) Attitudes toward mental retardation and eugenics: The role of formal education and experience *Journal of Developmental and Physical Disabilities*, 7(1):1-9.
- Kumar SG, Das A, Bhandary PV, Soans SJ, Kumar HNH, Kotian MS (2008). Prevalence and pattern of mental disability using Indian disability evaluation assessment scale in a rural community of Karnataka. *Indian Journal of Psychiatry*, 2008; 50: 21-23.
- Larson. R. and. Verma. S. (1999). How children and adolescents spend time across the world: work, play and developmental opportunities. *Psychological Bulletin*, vol. 125, No. 6 (November 1999), pp. 701-736.
- LeMaistre, J. (1985). Parenting. In S. E. Browne, D. Connors, & N. Stern (Eds.), *With the power of each breath: A disabled women's anthology*. Pittsburgh, PA: Cleis Press.
- Link, B., and Phelan, J. (1995). Social Conditions as Fundamental Causes of Disease, *Journal of Health and Social Behavior*, 35 (Suppl.): 80-94.
- Lister, R. 1997. *Citizenship: Feminist perspectives*, Basingstoke: Macmillan.
- Lennox NG, Diggins JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *J Intellect Disabil Res*. 1997 Oct;41(Pt 5):380-390.
- Lonsdale, S. (1990) *Women and Disability*. London: Macmillan.
- Lustig, D.C. and D.R. Strauser (2007): Causal Relationships between Poverty and Disability, *Rehabilitation Counseling Bulletin*.
- Madhavan, T.; Menon, D. K.; Kumari, R. Shyamala; Kalyan, Manjula (1990). Mental retardation awareness in the community. *Indian Journal of Disability & Rehabilitation*, Vol 4(1): 9-21.
- Meekosha, H. (2004) *Gender and Disability* (Draft entry for the forthcoming Sage
- *Encyclopaedia of Disability*). Available from:
- <http://www.leeds.ac.uk/disabilitystudies/archiveuk/meekosha/meekosha.pdf>
- Meekosha, H. and Dowse, H. (1997). 'Enabling Citizenship: Gender, disability and citizenship in Australia' *Feminist Review*, 57, Autumn, 49-72.
- Metts R. (2000). *Disability Issues, Trends and Recommendations for the World Bank*. Washington, DC: World Bank.
- Mini GK. (2006) *Disabled People in Kerala*. Disability Indian Network. 2006. Available at <http://www.disabilityindia.org/djartaug06A.cfm>
- Mont D. (2007). *Measuring Disability Prevalence*. Disability and Development Team. The World Bank Human Development Network Social Protection. 2007. Available at <http://worldbank.org/DISABILITY/Resources/Data/20070606DMont.ppt>
- Moore. K. and R. Yeo, and (2003): Including Disabled People in Poverty Reduction Work: Nothing about Us, Without Us, *World Development*, Vol. 31, No. 3 pp.571-590, 2003.
- Morris, J. (1991) *Pride Against Prejudice*. London: The Women's Press.
- Morris, J. (1989) *Able Lives: Women's experience of paralysis*. London: The Women's Press.
- Mostert Mark P., and Crockett Jean C. 1999-2000. "Reclaiming the History of Special Education for More Effective Practice." *Exceptionality* 8:133-143.

Reference

- NCPEDP (2004). University education in India for PWDs.
- O'Toole, Corbett Joan, & Doe, Tanis. "Sexuality and Disabled Parents with Disabled Children". In *Sexuality and Disability*, Vol20. No1, Spring 2002.
- Pati, B.K. (2011). Safe drinking water in Orissa : A long way to go. Available at http://odishatoday.com/viewnews.php?news_id=1943
- Perry, A. D (2002). Disability issues in the employment and social protection. ILO Bangkok, 2002
- Preiser, W.F.E., & Ostroff, E., (2001) Universal design Handbook. McGraw-Hill Professional
- Rao, A.N (2009). Poverty and disability in India. *Social Change* March 2009 vol. 39 no. 1 29-45
- Reid, Denise; Angus, Jan; McKeever, Pat; Miller, Karen-Lee. "Home Is Where Their Wheels Are: Experiences of Women Wheelchair Users" in *American Journal of Occupational Therapy* 2003 by The American Occupational Therapy Association, Inc. Vol. 57 \ (2), March/ April 2003, p.186-195
- Sainsbury, R., Hirst, M. and Lawton, D. (1995) Evaluation of Disability Living Allowance and Attendance Allowance DSS Research Report No. 41, Department of Social Security.
- Sevenhuijsen, S. (1998). *Citizenship and the Ethics of Care: Feminist considerations on justice, morality and politics*. London: Routledge.
- Shaul, S., Dowling, P. J., & Laden, B. F. (1985). Like other women: Perspectives of mothers with physical disabilities. In M. J. Deegan & N. A. Brooks (Eds.), *Women and disability: The double handicap*. New Brunswick, NJ: Transaction Books.
- Shermant Douglas F and Fuchs Lynn S. 1996. "A Historical Perspective on Special Education Reform." *Theory into Practice* 35:12-19.
- Simister J and A Yunis (1999). Cultural and its impact on rehabilitation program: a Palestinian perspective. In Leavitt RL (ed) *Cross-Cultural Rehabilitation: An international perspective for rehabilitation professionals*. London: WB Saunders. Singh, K. (January 28, 2007). Varanasi seer's memory is phenomena. *Tribune, India*.
- Singh A (2008). Burden of disability in a Chandigarh village. *Indian Journal of Community Medicine*, 2008; 33: 113-115.
- Technopak Advisors Pvt. Ltd., (Jan 2008) India Leisure & Entertainment Trends 2008-09 – Research report available at http://www.researchandmarkets.com/reports/649746/india_leisure_and_entertainment_trends_2008_09
- Traustadottir, R. (July 1990). OBSTACLES TO EQUALITY: The Double Discrimination of Women with Disabilities - Overview Article. Center on Human Policy. Available at <http://dawn.thot.net/disability.html>
- The Washington Times (5 Dec 2005). Disabled still face hurdles in job market.
- Thomas P. (2006). Mainstreaming disability in development: India country report. *Disability Knowledge and Research*; 2005.
- UNDP Human Development Report. Geneva, 1995.
- UNESCO, International Charter of Physical Education and Sport (21 November 1978) online: UNESCO http://www.unesco.org/education/nfsunesco/pdf/SPORT_E.PDF
- UN Convention on the Rights of Persons with Disabilities.
- United Nations, The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (20 December 1993) A/Res/48/96 online: UN Enable

- <http://www.un.org/esa/socdev/enable/dissre00.htm>
- U.S. Census Bureau. (2004): Survey of Income and Program Participation 1991, Retrieved February 2, 2005, <http://www.census.gov/population/pop-profile/disability>.
- Verplanken, B., Meijnders, A., & van de Wege, A.J. (1994). Emotion and cognition: Attitudes toward persons who are visually impaired. *Journal of Visual Impairment and Blindness*, 88, 504-511.
- Wates, M. (1997). *Disabled Parents: Dispelling the Myths*. Cambridge, UK: National Childbirth Trust.
- WHO/UNICEF sanitation Report. 2004. http://www.sulabhinternational.org/sm/magnitude_sanitation_problemnational_global.php
- Wittenburg, D., and M. Favreault (2003): *Safety Net or Tangled Web? An Overview of Programs and Services for Adults with Disabilities*, Occasional Paper Number 68. Washington, DC: Urban Institute. Retrieved February 19, 2007, from http://www.urban.org/uploadedpdf/310884_OP68.pdf
- Wolfensberger, W. (2000): A Brief Overview of Social Role Valorization, *Mental Retardation*, 38, 105-122.
- Woolfson RC (1984) Historical perspective on mental retardation. *American Journal of Mental Deficiency* (1984) Volume: 89(3): 231-235
- The World Bank. (2007). *People with disabilities in india: From Commitments to Outcomes*. Human Development Unit, South Asia Region.
- Yeo, R. (2001): *Chronic poverty and disability*. Background paper number 4. Somerset, UK: Chronic Poverty Research Centre. ISBN Number: 1-904049-03-6
- Yoshitaka, I. (2006) *Leisure and quality of life in an international and multi cultural context: what are major pathways linking leisure to quality of life?* *Social Indicators Research*. Springer. Vol 82 (2), Pages: 233-264



With the support of WCD department we have completed the disability profiling of Odisha. The study is the first of its kind in India. It has come up with a lot of information on the socio-economic profile of people with disabilities in the state, the societal attitudes faced by them, and covers all major aspects of the lives of disabled persons vis-à-vis gaps in mainstreaming. We will feel humbled and honored if the document in any way will be an asset for government, NGOs, research workers, development organizations, corporate houses, banks, research institutions, educational bodies and any person or body requiring information on disability scenario to forge a pathway for long term planning, inter-organizational / departmental partnership and evolution of new schemes for the empowerment of persons with disabilities.



A/98, Budha Nagar, Bhubaneswar-751006
Tel : 0674-2313313, 9238106667(O)
Fax : 0674-2313313/2311957/2311964
Email : swabhiman.bhubaneswar@gmail.com
website : www.childrenfestival.org/www.swabhiman.org