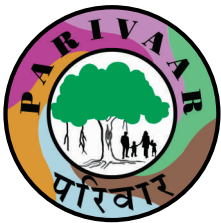


A Study on Understanding the Socio-Economic Status of Persons with Intellectual and Developmental Disabilities (PwIDDs) and their Families in India

Conducted by



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Bangalore**

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PARIVAAR[®]

*(A National Confederation of Parents' Organizations for Persons with
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Chronology of PARIVAAR

1994

- ◆ Decision to form a National Federation of Parents' Associations at the Inclusion International League of Societies for the Mentally Handicapped (ILSMH) now known as Inclusion International

1995

- ◆ Organizes the National Parents' Meet, Mumbai, Supported by NIMH

1996

- ◆ Formation of National Federation Parents' Associations took place at Bangalore at the National Parents' Meet, supported by NIMH legally registered with reg. office at Delhi

1997

- ◆ National Parents' Meet, Calcutta, Supported by NIMH
- ◆ Publication of Quarterly Newsletter

1998

- ◆ National Parents' Meet, Indore, Supported by NIMH

1999

- ◆ National Parents' Meet, Ernakulam, Supported by NIMH

2000

- ◆ Enters into MOU with Inclusion International for a 3 year Parent Mobilization Action Group (PMAG India) Project
- ◆ Becomes full member of Inclusion International
- ◆ National Parents' Meet, Rohtak, Supported by NIMH
- ◆ Parivaar enters into partnership with Libenshilfe, Austria

2001

- ◆ National Parents' Meet, Pune, Supported by NIMH

2002

- ◆ National Parents' Meet, Bangalore, Supported by NIMH
- ◆ Instituted Smt. Premlata Peshawaria National Award

2003

- ◆ National Parents' Meet at Bhopal, Supported by NIMH
- ◆ Roundtable Conference at Chennai

2004

- ◆ National Parents' Meet at Nagpur, Supported by NIMH

2005

- ◆ Supported by Christoffel-Blindenmission, South Asia Regional Office, South, Bangalore
- ◆ National Parents' Meet at Coimbatore, Supported by NIMH

2006

- ◆ Five year partnership with Christoffel-Blindenmission, South Asia Regional Office, South, Bangalore. (2006-2010)
- ◆ Research on Processes of Change in the lives of Persons with intellectual Disability - a study conducted by Parivaar, Supported by SIDA, Sweden

Continued on Back Inner cover...

2007

- ◆ Support from Christoffel-Blindenmission, South Asia Regional Office, North, Bangalore for Northern states
- ◆ National Parents' Meets at Durgapur & Bhubaneswar, Supported by NIMH

2008

- ◆ Support from Christoffel-Blindenmission, South Asia Regional Office, North, Bangalore for West Bengal & Odisha
- ◆ Launches four Regional Parents' Meets supported by NIMH
- ◆ Launches "Supported Decision Making (SDM)" Project in Dehradun with support from Inclusion International & National Trust
- ◆ Regional Parents' Meet Launched supported by NIMH
- ◆ National Parents' Meet, Hyderabad
- ◆ Launching of Self Advocacy Movement and formation of Self Advocates Forum of India (SAFI)

2009

- ◆ Partnership with Disability Rights Fund (DRF, USA) for SDM project launched in Bhilai, Bangalore, Hyderabad, Bhubaneswar
- ◆ Six Regional Parents' Meets supported by NIMH
- ◆ National Parents' Meet at Ernakulam, supported by NIMH

2010

- ◆ Demonstration Project on SDM at Delhi launched
- ◆ Eight Regional Parents' Meet conducted, supported by NIMH
- ◆ National Parents' Meet at Aurangabad, supported by NIMH
- ◆ Formation of State Federations in West Bengal, Odisha, Maharashtra, Karnataka, Kerala, Andhra Pradesh and Tamil Nadu with CBM support
- ◆ Partnership with CBM, South Asia Regional Office, South & North, Bangalore continues

2011

- ◆ Two Year National Coalition Project on 'Hear Our Voices' – A parallel Report on UNCRPD supported by DRF launched
- ◆ National Parents' Meet at Jamshedpur, supported by NIMH
- ◆ Eight Regional Parents' Meets Conducted, supported by NIMH

2012

- ◆ Partnership with CBM, South Asia Regional Office, South & North, Bangalore continues
- ◆ Accreditation of State Federations by Parivaar: Andhra Pradesh, Karnataka, Kerala, Maharashtra, West Bengal and Tamil Nadu
- ◆ SDM project supported by DRF in Kerala
- ◆ National Parents' Meet at Navi Mumbai, supported by NIMH
- ◆ Ten Regional Parents' Meets, (2012-13) supported by NIMH
- ◆ Awareness program at Guwahati, Assam for families supported by National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD)
- ◆ Parivaar Website re-launched: www.parivaarnfpa.org supported by AusAid & CBM
- ◆ Publication of Handbook for mentors of Self Advocates - Funded by AusAid & CBM
- ◆ Research Publication on Socio-economic Status of Persons with Intellectual and Developmental Disabilities & their Families - funded by AusAid & CBM

Organisational Chart of PARIVAAR



**A Study on
Understanding the
Socio-Economic Status of Persons with
Intellectual and Developmental Disabilities
(PwIDDs) and their Families in India**

2011-12



PARIVAAR

(A National Confederation of Parents' Organizations for
Persons with Intellectual & Developmental Disabilities)

Ajin Kumar Sen

President



Acknowledgement

Parivaar extends its heartfelt gratitude to CBM, South Asia Regional Office of South and North, Bangalore and AusAid for providing the financial assistance to undertake this study on the Socio-Economic Status of PwIDDs and their families in India.

We are also thankful to the Parivaar State Federations and its member Associations in the states of Andhra Pradesh, Karnataka, Kerala, Maharashtra, Tamil Nadu, Odisha and West Bengal and Parents' Associations in Madhya Pradesh, Chhattisgarh, Delhi, Goa and Meghalaya, who have undertaken the survey in their respective States and provided us with valuable data.

A special mention of thanks goes to Saarathy-PAMMAC, Coimbatore for coordinating this research activity with Bharathiar University and Dr. M.N.G. Mani, Managing Trustee, UDIS Forum, Coimbatore, for his valuable suggestions and inputs.

Parivaar wishes to place on record its appreciation to all the parents who had volunteered to provide the information. Parivaar is indebted to Dr. A. Sethuramasubbiah, Professor & Head, Dr. R. Arjunan, Assistant Professor, Dr. S. Udhayakumar, Faculty and Ms. R. Madhula, Research Scholar, Department of Social Work, Bharathiyar University, Coimbatore for undertaking the in-depth analysis of the survey, validating the data and interpreting its findings.

Parivaar wishes to place its appreciation to Ms. J.S. Suma, Office Manager and all other support staff of Parivaar, Mr. M.R. Visvanathan, ICEVI Secretariat, Coimbatore for their cooperation. Our sincere thanks are due to Market Research Service, Coimbatore, Tamil Nadu for statistical analysis of the survey.

We will fail in our duties if we do not acknowledge the contributions made by Mr. J P Gadkari, Director, Projects & Development, Parivaar, under whose leadership the projects was initiated and Mr. Vijay Kant, Chief Operations Manager, Parivaar and Mr. K. Sankararaman, Parivaar State Program Coordinator, Tamil Nadu, who, in their enthusiasm, dedication and untiring efforts have made this study not only possible, but also a successful one.

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Professor & Head



Foreword

Inclusive education and skill development are vital requirements in Persons with Intellectual and Developmental Disability (PwIDDs) in their progress towards independence and sustainability aspects. The society should learn the lesson on nature of disability and try to understand that PwIDD is a human being too. There is need for paradigm shift from “sympathy approach” to “human rights approach” in understanding the PwIDDs at individual level.

The organization ‘PARIVAAR’ is a parental network body to initiate campaign & lobbying activities, research, and IEC promotional activities for the welfare of families and PwIDDs at national level in the area of socio-economic condition, status of welfare measures, psycho-social conditions and so on. They had more meaningful milestones in facilitating government authorities towards the well being of PwIDDs in India.

Based on their experience, ‘PARIVAAR’ conducted a national level sample survey on socio-economic status exclusively among PwIDDs in India. The study covered all the regions like southern states, northern states as well as the union territories in India. The findings of the study are very crystal clear and exposed the real socio-economic status of PwIDDs in the Indian context.

I take this opportunity to place a word of appreciation to ‘PARIVAAR’. Its attempt is path breaking and innovative in understanding the socio-economic status of PwIDDs in India.

I hope the readers and the future researchers will feel and experience the professional touch and its usefulness of this study in the areas of disability.

Dr. A. Sethuramasubbiah

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Executive Summary

The socio-economic research study has brought out certain findings that bear witness to the status of persons with intellectual and developmental disabilities (PwIDDs) and their families in India. The findings are highlighted in this executive summary. The study findings show that the disability prevalence is more among males (59.5%) than females (40.5%). Majority of the respondents (71%) were children and adults with mental retardation followed by multiple disability (19.4%), cerebral palsy (5.1%) and Autism (4.5%) respectively. The study revealed that about 41.5% of the parents were illiterate and 38% were from unorganized sector. Their socio-economic condition remains very poor. Among the surveyed, the minority group accounts for 7% Muslims and Christians and 15.3% SC/ST.

While analyzing access to government services, it was found that the services did not reach the needy properly. Even the Disability Identity Card, a basic requirement for availing any facility from government, nearly 60.7% did not have access to the ID Card and 80.5% did not avail disability scholarship, 73.7% were not able to avail pension scheme, 72.9% were not able to access Niramaya Health Insurance card and 60% did not avail railway concession facilities. In general 40% of the respondents did not avail any services whatsoever. The data shows that the respondents and their families faced practical problems in getting disability related services from the respective state governments.

Out of the total respondents only 32.7% were adults and only 9.6% reported having guardianship certificate. It is significant to note that about 49% of respondents were from the below poverty line category. The burden of spending more money, time and energy for their disabled children/adults adds to the poverty of the family. Due to this, more families are pushed to BPL category. In response to the marital status of PwIDDs only 37 persons (0.5%) were married. There was a significant percentage who do not have siblings (35.4%). The siblings provide not only physical support but also are role models and crucial link to adult life of PwIDDs. In the absence of the siblings the plight of the IDD after the demise of their parents is a big question mark. Among the total respondents female population was 41% and in that group 11.5% were from the SC/ST community and 40.2% belonged to BPL families. Women faced difficulties in getting physical and personal care from the family members and are discriminated sexually and this is more acute in case of adult women. Among the BPL families about 32% live with single parent (with mother 27.4% & with others 4.7%). The PwIDDs who live with a single parent are more

vulnerable and social security is a serious threat. Among the multiple disability respondents, only 31% could avail aids and appliances from the government and 69% did not have access to the aids and appliances.

The study suggests that good quality services and timely interventions are needed to get the government schemes like Niramaya health card, railway concession, and Disability Identity card and so on. The capacity building, social security and sustainable livelihood programs are needed to improve the quality of life of PwIDDs.

The UN declarations and National Acts emphasize human rights approach but not charity mode in providing services. There is an urgent need for special attention to promote effective policy and program implementation mechanism for persons with Intellectual and Developmental Disabilities in India.

Introduction and Methodology

1.1 Introduction

Disability indicates the permanent loss of the functions of the particular organ to the extent that the individual cannot fully participate in the social and vocational pursuits. The disability surrounded by a distressing environment makes the person a handicap. Therefore, a handicap is made and not acquired. Disabled individuals who live in the most restrictive environment experience handicapping conditions. There are nearly 2.2 crores of people in India who are affected by disability in one way or the other. This constitutes more than 2% of the total population of India (Census data 2001).

Globally it is estimated that about 10% of the world's population experiences some form of disability or impairment. The number of people with disabilities is increasing due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life, creating overwhelming demands for health and rehabilitation services. The disability wise classifications of Persons with Disability (PwDs) as per the Census 2001 are as follows: Movement (28%), Seeing (49%), Hearing (06%), Speech (07%) and Mental (10%).

1.1.1 Condition of Disability

There are several definitions of disability, ranging from the very narrow to the very broad, from the medical to the social model. People are often labeled as 'disabled', because they appear different from the rest in society on account of their appearance and / or behavior. Disability is a condition or function judged on the basis of impairment related with the usual standard of an individual. The term is used to refer to individual functioning, including physical, sensory, cognitive or intellectual impairment, mental illness, and conditions. According to WHO report 2001, mental disorders affect one out of four people worldwide and India is not an exception. This places mental disorders among the leading causes of ill health and disability.

1.1.2 Understanding Intellectual and Developmental Disabilities (IDDs)

There are four categories of disability that are covered under this survey namely, Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. These disabilities are covered under the National Trust Act of 1999 and universally termed as intellectual and developmental disabilities (IDDs). These disabilities are in fact caused due to injury to the

brain and damage to the central nervous system. This could be due to several environmental factors which deprive the brain of oxygen before, during or after birth. These are conditions which are not contagious or progressive. They cannot be cured by drugs or surgery. Early detection and intervention improves their skills.

1.1.3 Autism

Autism is a developmental disability that is often misunderstood by many. Autism is an invisible condition compared to other disabilities. It is a complex developmental disability that appears during the first three years of life. It has been classified as Pervasive Developmental Disorder (PDD), a term meant to indicate severe and interrelated impairment in several areas of development; social skills, communication skills, or the presence of stereotyped behavior, interests and activities.

Autism and the associated behaviors with it, have been estimated to occur in as many as 2 to 6 in 1000 individuals. This neurological disorder which affects the social and emotional areas of the brain leading to challenges in communication, social relationships and imagination. It is more common in boys than in girls. Autism is the fastest-growing serious developmental disability in the world. More children will be diagnosed with autism than with diabetes, cancer, and HIV/AIDS put together. There is no medical detection or cure for autism, but early diagnosis and intervention may improve their condition.

1.1.4 Cerebral Palsy (CP)

Cerebral Palsy means damage to the brain. A person with Cerebral Palsy generally has more than one impairments. Drugs and surgery cannot cure this condition. Early detection and training is vital. Early intervention focuses on speech, movement and education of a child with cerebral palsy. It also requires intervention by physio, occupational and speech therapists, community based rehabilitation workers and special educators.

1.1.5 Mental Retardation (MR)

Mental Retardation is a delay, or slowness, in a child's mental development. A child with mental retardation learns things more slowly than other children of the same age. Persons with mental retardation have been categorized into mild, moderate, severe and profound categories depending on the degree of mental retardation. There is noticeable deficiency in the development of motor, cognitive, social and language functions.

To explain further, a child with mental retardation faces difficulties in learning, in using past experiences for the solution of present problems. He finds it difficult to remember, to understand and adjust to different situations. He does not develop mentally or even physically at the same rate as other children of the same age. For example, a child may be

8 years old but may have the abilities of a 4 or 5 year old child, or a 12 year old child may behave like a 4-5 year old or even less. Many of these children, if given suitable and timely training may learn to take care of their basic needs like drinking, eating, bathing, dressing etc. There will, however, be some children who will always need to be cared for in some ways.

1.1.6 Multiple Disabilities (MD)

“Multiple Disabilities” means a combination of two or more disabilities as defined in clause (i) of section 2 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (1 of 1996).

This one category of people have been marginalized for a long time. Now by the efforts of National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai and by NGOs like Sense International, some training centres have been started. Persons with multiple disabilities also need to be recognized like Cerebral Palsy with Mental Retardation or Mental Retardation with Visual Impairment etc. This combination can occur in any order.

a. Prevalence of Disability

Globally, the prevalence of disability is at 4% to 10%. 4% in developing countries and 7% in industrialized countries. The prevalence is estimated to be around 1.5 to 2.13% in South East Asian member countries and 1.8% to 2.2% for India (WHO).

b. Prevalence of disability in India

Different prevalence rates for disability are available in India. According to the Census 2001, people with disabilities in India constitute 2.13 % of the total population (Census 2001). Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, loco-motor and mental disabilities (Census 2001).

In contrast, the National Sample Survey Organization (NSSO) estimated that the number of persons with disabilities in India is 1.8% (49-90 million) of the Indian population (NSSO 2002), that 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate. In its report “Incidence of disability in India” in 2002, the NSSO estimated that the incidence rates for males were 77 and 75 per 100,000 respectively in rural and urban India as against 61 and 58 per 100,000 respectively among females during 2001-2002. Urban/rural differences varied, ranging from 2 to 117 per 100,000 persons in rural India and from 11 to 132 per 100,000 persons in urban India.

Indications are that 2011 census may reveal a higher figure. Low level of literacy, few jobs and widespread social stigma are making disabled people among the most excluded in

India. Despite the Sarva Shiksha Abhiyan and Right to Education (RTE), Children with intellectual and developmental disabilities are less likely to be in school; disabled adults are more likely to be unemployed, and families with a disabled member are often worse off than average. (Dr. Sruti Mohapatra, 2012)

In the light of the above, it is especially important for policy makers and advocacy organizations to have access to a wide variety of data on people with disabilities in order to better understand their needs and assess how existing programmes and policies are implemented, and analyze the gaps that exist in accessing various benefits and plan for the future.

1.1.7 Policies and Guidelines for Persons with Disabilities (PwDs) in India

The protection of the rights of PwD is covered by four Acts in India. The details are given below.

i. Mental Health Act 1987

Mental Health Act came into effect in all the states and union territories of India in April 1993 and replaced the Indian Lunacy Act of 1912. This Act consolidated and amended the law relating to the treatment and care of mentally ill persons and to make better provision with respect to their property and affairs.

In 2002, the Act was implemented in 25 out of 30 states and Union Territories. Under the Mental Health Act 1987, each state is required to constitute a State Mental Health Authority (SMHA) to ensure effective and equitable enforcement of the provisions of the Act. The primary role of the SMHA is in planning, implementation and monitoring of mental health programme/activities. This act also removed persons with intellectual disability (Mental Retardation) from the purview of mental health act.

ii. Rehabilitation Council of India Act 1992

This Act sets out to regulate the training of professionals in rehabilitation and sets out a framework for a Central Rehabilitation Register. In order to give statutory powers to the Council for carrying out its duties effectively the Rehabilitation Council of India Act was passed by the Parliament which came into force with effect from 1993.

The amendment in the Act in 2000 gave the additional responsibility of promoting research to the Council. The major functions of the council include the recognition of qualifications granted by Universities in India for Rehabilitation Professionals and also the recognition of qualification by Institutions outside India.

iii. The Persons with Disabilities Act 1995

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 was enacted in 1995 to give effect to the Proclamation on the Full

Participation and Equality of the People with Disability in the Asian & Pacific Region (Beijing 1992). The aims and objectives of the Act are:

- + To spell out the responsibility of the state towards the prevention of disabilities, protection of rights, provision of medical care, education, training, employment and rehabilitation of persons with disabilities;
- + To create a barrier free environment for person with disabilities in the sharing of development benefits, vis-a-vis non disabled persons;
- + To counteract any situation of abuse and exploitation of persons with disabilities;
and
- + To make special provision for the integration of persons with disabilities into the social mainstream.

a. Obligations on governments

In order to achieve its aims and objectives the act imposes obligations on the appropriate governments (central, state and local governments) in the following areas:

- Prevention and early detection of disabilities (Section 25)
- Providing equality in education (Section 26, 27, 28, 29, 30, 31)
- Providing equality in employment (Section 32, 33, 34, 35, 37, 38, 39, 40, 41, 47)
- Providing affirmative action programmes in providing aids and appliances to persons with disabilities and preferential allotment of land at concessional rates for housing, setting up businesses, setting up of special schools, establishment of research centres, establishment of factories by entrepreneurs with disabilities (Section 42, 43)
- Providing non-discrimination by removing physical barriers (Section 44, 45, 46)
- Providing research manpower development (Section 48, 49)
- Setting up institutions for persons with disabilities (Section 52)
- Providing social security for the disabled (Section 56, 67, 68)

b. Prevention and early detection of disabilities

In order to prevent the occurrence of disabilities, the appropriate government authorities have to (within their economic capacity and development):

Undertake surveys, investigations and research concerning the cause of occurrence of disabilities; promote various methods of preventing disabilities; screen all the children at least once in a year for the purpose of identifying “at risk” cases; provide facilities for training the staff at the primary health centres; sponsor awareness campaigns and disseminate information on general hygiene, health and sanitation; take measures for

pre-natal and post-natal care of mother and child; educate the public through the pre-schools, schools, primary health centres, village level workers and Anganwadi workers; create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted (Section 25).

c. Education

In order to provide equal opportunities for the disabled in education, the appropriate government and local authorities have been entrusted with: ensuring that every child with disability has access to free education in an appropriate environment till 18 years of age; promoting the integration of students with disabilities in normal schools; promoting setting up of special schools in government and private sector in such a manner that children with disabilities living in any part of the country have access to such schools and equipping these schools with vocational training facilities; conducting part-time classes for children with disabilities who have completed education up to class five, but could not continue their studies on a whole-time basis; conducting special part-time classes for providing functional literacy for children in the age group of sixteen and above; imparting non-formal education by utilizing the available manpower in rural areas after giving them appropriate orientation; imparting education through open schools or open universities; conducting classes and discussions through interactive electronic or other media; providing special books and equipments needed for every child with disability free of cost (Section 27).

d. Comprehensive schemes are to be prepared by the government for:

Transport facilities to the children with disabilities or alternative financial incentives to parents or guardians to enable their children with disabilities to attend schools; the removal of architectural barriers in schools, colleges or other institution, imparting vocational and professional training; the supply of books, uniforms and other materials to children with disabilities attending school; the grant of scholarship to students with disabilities; setting up of appropriate forums for the redressal of grievances of parents, regarding the placement of disabled children; suitable modification in the examination systems; restructuring of curriculum for the benefit of children with disabilities.

All government educational institutions and other educational institutions receiving aid from the government are to reserve not less than 3 per cent of its seats for disabled persons. To implement the educational rights of the disabled to the full extent, the appropriate Governments have to set up adequate teachers' training institutions and assist the national institutes and other voluntary organisations to develop teachers' training programmes specializing in disabilities, so that requisite trained manpower is available for

special schools and integrated schools for children with disabilities. (Section 29) It is also entrusted with the duty of initiating research by official and non-governmental agencies for the purpose of designing and developing new assistive devices, teaching aids, special teaching materials or such other items as are necessary to give a child with disability equal opportunities in education (Section 28).

e. Employment

The appropriate governments are to identify posts in government establishments, which can be reserved for disabled persons and review the list of posts at periodic intervals (not exceeding three years) (Section 32).

At least three percent of vacancies in every government establishment are to be reserved for persons with disabilities, out of which one per cent each shall be reserved for persons suffering from blindness or low vision, hearing impairment and loco motor disability or cerebral palsy.

However, Intellectual disability is not covered under this reservation policy.

The central government may exempt any establishment from the above requirements if the nature of work in such establishments is such that disabled persons are unable to work in such establishments (Section 33).

If a vacancy cannot be filled up due to non-availability of a suitable disabled person, the vacancy is to be carried forward to the next recruitment year and if in that next recruitment year, a suitable person with disability is not found, the post is to be filled by an interchange of categories of disabled persons. Only if there is no suitable disabled person available for the job, can an able person be employed (Section 37).

In order to ensure employment of disabled persons, schemes are to be formulated by the appropriate government.

f. Affirmative action

The appropriate governments have to frame schemes to provide aids and appliances to disabled persons (Section 42). Special schemes are to be notified for the preferential allotment of land at concessional rates for: Housing; setting up business; setting up special recreational centres' establishment of special schools; establishment of research centres; establishment of factories by entrepreneurs with disabilities (Section 43).

g. Non-discrimination

In order to create a physical barrier-free environment for disabled persons, the appropriate governments or local authorities have to (in their economic capacity and development) take special measures to:

Adapt rail compartments, buses, vessels and aircrafts in such a way as to permit easy access to such persons; 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 (Section 44); install auditory signals at red lights in the public roads for the benefit of persons with visual handicap; make curb cuts and slopes in pavements for the easy access of wheel chair users; engrave the surface of the zebra crossing for the blind or for persons with low vision; engrave the edges of railway platforms for the blind or for persons with low vision; devise appropriate symbols of disability; provide warning signals at appropriate places (Section 45); provide ramps in public buildings; provide Braille symbols and auditory signals in elevators or lifts; provide ramps in hospitals, primary health centers and other medical care and rehabilitation institutions (Section 46).

h. Research and manpower development

The appropriate government and local authorities are entrusted with sponsoring and promoting research in the following areas:

Prevention of disability; rehabilitation including community based rehabilitation; development of assistive devices including their psycho-social aspects; job identification and on site modifications in offices and factories (Section 48).

Universities, other institutions of higher learning, professional bodies and non-governmental organisations that undertake research on special education, rehabilitation and manpower development are to be provided financial assistance by appropriate governments for undertaking research for education, rehabilitation and manpower development (Section 49).

i. Institution for persons with severe disabilities

The concerned government may establish and maintain institutions for persons with severe disabilities at such places it thinks fit or recognise any private institution. (Section 56).

j. Social security

While formulating rehabilitation policies, the appropriate governments have to consult non-governmental organisations working in the field of disability. Within their economic capacity and development they are to undertake rehabilitation of all disabled persons for which financial assistance shall be given to non-governmental organisations working in the fields of disability (Section 66).

Insurance schemes or alternate security schemes are to be framed by the appropriate government for the benefit of its employees with disabilities (Section 67).

Schemes are also to be framed for payment of an unemployment allowance to persons with disabilities who have registered with the special employment exchange for more than two years and have not been placed in any gainful occupation (Section 68).

k. Implementation agencies

The act has set up a central coordination committee at the national level to serve as a national focal point for disability matters to facilitate the continuous evaluation of a comprehensive policy towards solving the problems faced by disabled the persons (Section 8). At the state level a state coordination committee has been set up (Section 13).

To assist the central coordination committee and state coordination committees, a central executive committee (Section 10) and a state coordination committee have been set up (Section 23).

The Chief Commissioner and Commissioners for persons with disabilities have to safeguard the rights of persons with disabilities and submit reports to the government on implementation of the act (Sections 57, 58, 59, 60, 61, 62, 63, 64, 65).

If there is any violation of the act, the aggrieved person can approach the head of the establishment under which he/she is employed or the Chief Commissioner or the Commissioner for Persons With Disabilities or the High court under article 226 of the Constitution of India or the Supreme Court under article 32 of the Constitution of India or even the National or State Human Rights Commissions.

The PwD Act recognized mental retardation as a disability but failed to make any provision for their rehabilitation and welfare. Despite its shortcomings, it is considered as a landmark legislation that comprehensively addressed the issue of disability in our country.

iv. The National Trust Act 1999

The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 provides for the constitution of a national body for the welfare of persons with the above disabilities.

The Act aims to empower those with disability to live as independently as possible, within their community and their own families; and to support persons with disability who have no family support. This Act gives the right to parents, or relatives (or organizations registered with the Board) to ask for the appointment of a guardian for the person with disability. Apart from dealing with guardianship issues, the Act also gives the Board the responsibility of receiving and managing bequests of movable property for the benefit of those with challenges.

The main objectives are:

- to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
- to strengthen facilities to provide support to persons with disability to live within their own families;
- to extend support to registered organization to provide need based services during the period of crises in the family of persons with disability;
- to deal with problems of persons with disability who do not have family support.

The following are the schemes of the National Trust :

a. NIRAMAYA:

This is a health insurance scheme for any person below the poverty line with the four disabilities under the National Trust. The insurance cover is up to Rs. 1 lakh for a vast range of health services from OPD to cashless hospitalisation. The scheme is free for persons with family income up to Rs. 15,000 per month and on a payment of Rs. 500/- per person for higher income group in the entire country (excluding J&K). This scheme covers about 96,344 PwIDDs in the country.

b. GUARDIANSHIP:

Under section 14 of the National Trust Act, the Local Level Committee (LLC) headed by the District Collector is empowered to appoint legal guardians for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. It also provides mechanism for monitoring and protecting their interests including their properties. The National Trust Annual Report (2010-11) reported that between the years 2003 to 2011, a total of 25,651 PwIDDs were given guardianship certificates (Source : National Trust).

c. GHARAUNDA

Group Home And Rehabilitation Activities (GHARAUNDA) Under National Trust Act for Disabled Adults is a new scheme for providing Life Long Shelter & Care to Persons with Disabilities in Group Homes.

d. SAHYOGI

It's a new & revamped scheme of Caregivers Training & Deployment. A new training module has been designed and a system of training & deployment of Caregivers has been provided for under the scheme.

e. SAMARTH:

It's a Centre Based Scheme (CBS) which was introduced in July 2005 for residential services - both short term (respite care) and long term (prolonged care). Activities in a

Samarth Centre should include early intervention, special education or integrated school, open school, pre-vocational and vocational training, employment oriented training, recreation sports etc. The facilities in the home shall be available to both- men and women- on 50-50% basis and shall cover all the four disabilities under the National Trust.

f. ASPIRATION:

This is an early intervention programme for school readiness. The scheme is to work with children of 0-6 years with developmental disabilities, to make them ready for mainstream and special schools.

g. REMOTE AREA FUNDING:

The objective of this scheme is to stimulate National Trust activities in unrepresented districts. Under the scheme, fund is provided to set up an NGO, including parents association and then to carry out activities for the welfare of persons with National Trust disabilities.

h. GYAN PRABHA:

Scholarship Scheme is supported for doing post schooling and any employment oriented course. Under the Scheme, a monthly scholarship of Rs. 700 shall be paid for up to 1 year. Any PwIDDs who has done any schooling or has not done any schooling at all can also get scholarship.

i. ARUNIM:

Association for Rehabilitation under National Trust Initiative of Marketing (ARUNIM) has been launched to help PwIDDs in product designing, production processes, packaging and marketing enabling them to live a life with dignity and independence. (Source: National Trust website).

1.1.8 National Policy for Persons with Disabilities

The National Policy enunciated in February 2006 recognizes that Persons with Disabilities are a valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. Its aim is to ensure better coordination between various wings of the State and Central Governments.

1.1.9 State Government Schemes for Persons with Intellectual and Developmental Disabilities (PwIDDs) in India

The State governments in India provide monthly maintenance allowance or pension or whatever name the schemes may be called; provide financial assistance to below poverty line category of persons with disability (PwDs). These schemes vary from State to State. Here some examples of the state government schemes:

i. Odisha Government Scheme

In the state of Odisha, Pension of Rs. 400 per month is given to those PwIDDs whose family falls under BPL category or if the disability of the PwIDD is over 75%.

ii. West Bengal Government Scheme

In the State of West Bengal, Rs. 700 per month is given to those PwIDDs who fall under the BPL category.

iii. Kerala Government Scheme

In Kerala, all Persons with intellectual and developmental disabilities (PwIDDs) who attend special schools irrespective of family income, will get financial assistance to the extent of up to Rs. 14,500/- per annum, which includes a scholarship amount of Rs. 750 PM; yearly dress allowance Rs. 750; educational material allowance Rs. 1,250 PA and conveyance allowance up to Rs. 5,000 PA. However, in practice this amount may be reduced depending on the financial viability of the local self government, (Panchayat) who are the implementing agency for providing assistance to disabled persons in their Panchayat.

An amount of Rs. 400 per month will be paid to only those PwIDDs who are not attending special schools and whose family income is below Rs. 20,000 per annum. There is also a caretaker allowance for those severely disabled at the rate of Rs. 400 per month. This pension is disbursed through the local self government.

iv. Tamil Nadu Government Scheme

In Tamil Nadu, the financial support given to PwIDDs is called as “Maintenance Grant” and the eligibility is the Disability percentage. All the PwIDDs, whose disability is over 60%, irrespective of their family income, are eligible for this grant which is Rs. 1,000 per month. Alternatively, there is a scheme called PHP (Physically Handicapped Pension - Rs. 1000 per month) administered through revenue department which can be availed by PwIDDs as well. Free bus passes (including the escort) are issued for PwIDDs who are attending special schools.

As per the Performance budget published by the department for the welfare of the differently abled, the website of Government of Tamil Nadu says a total of 77,112 PwIDDs were given maintenance grant in the year 2011-12. As per census 2001 the PwIDDs population in the state was 1,27,521. We should also consider the rise in disability population since 2001 to 2012.

v. Karnataka Government Scheme

In the State of Karnataka, PwIDDs who fall under BPL Category, a monthly financial assistance of Rs. 400/- is given and for those with Severe disability (75% and above) and belonging to BPL category are given 1000 per month.

vi. Andhra Pradesh Government Scheme

In the state of Andhra Pradesh, an amount of Rs. 500 per month is given to those PwIDDs who fall under the BPL category.

vii. Maharashtra Government Scheme

In the State of Maharashtra, there is no pension scheme or maintenance grant scheme for PwIDDs. For those PwIDDs who are under BPL category and if they attend special school they will be given scholarship which invariably goes to the special schools.

viii. Union territory of Puducherry Scheme

In the State of Puducherry (UT), it is called Monthly Financial Assistance and it is a 3 tier system. For PwIDDs with 40 to 65% disability, Rs. 1,100 per month is given, for 66 to 85% disability Rs. 1,400 per month is given and for 86 to 100% disability Rs. 1,750 per month is given. There are no income criteria.

1.1.10 Review of Related Studies

The preliminary step to conduct research in any field demands a baseline data about the prevalence, incidence and distribution of a specific population. There is clear lack of information regarding the number of individuals with Intellectual and Developmental Disabilities (IDD) in India. For example, during the 2001 census, it became particularly evident that individuals with IDD were not being identified as a separate disability. In 2002, the Census Bureau of India only reported 2 million cases of intellectual disabilities, compared to the WHO's estimates of 31 million.

The Census Bureau has identified two reasons for this discrepancy. First, people are unable to identify individuals with IDD because they do not understand what intellectual disabilities are. High levels of illiteracy and predominantly rural/agrarian communities, individuals with mild IDD are not easily recognizable because they seem to function like everyone else in the community (Girimaji, et al. 2001). In developing countries like India,

unlike individuals who have genetic disabilities, those with mild IDD, often caused by environmental factors such as malnutrition and under stimulation, may have no physical features that distinguish them from others. Second, families tend to withhold this information because they fear being shunned or stigmatized by the community (Census Bureau, 2001).

Recently a study was undertaken by SWABHIMAN in collaboration with Women & Child Development Department of Government of Odisha. This is a very comprehensive study. It has attempted to capture the profile of different categories of persons with disabilities in the aspect of public perception, access, population, knowledge of laws, justice & entitlements, education, livelihood, employment, poverty, health & sanitation, marriage & parenthood, social life & leisure, political participation and discrimination. (A Profile of Disability on Odisha; Trends, Development & Dynamics, April, 2012).

Although linkages between relative poverty and disability are often noted, they have not been systematically studied in particular reference to PwIDDs. The information about socio-economic status of intellectual disability in developing countries is very limited, the literature tends to focus on what is generally known about health, disabilities, poverty and vulnerable populations, and relies heavily on anecdotal evidence and case studies.

Therefore, one tends to rely on Human Development Index (HDI) of the government in analyzing the socio-economic status of disability as a tool. In a study conducted by Santa Memorial Rehabilitation Centre, Bhubaneswar with government of India & UNDP support, they used the state level Human Development reports of Orissa, Chhattisgarh and West Bengal while studying whether there is any relationship between socio-economic backwardness and prevalence of disability among women with disabilities.

The British Department for International Development (DFID) has recognized that, 'disability is a major cause of social exclusion and it is both the cause and consequence of poverty' (DFID 2000). Recent World Bank studies contend that half a billion disabled people are undisputedly amongst the poorest of the poor (Metts 2000) and are estimated to comprise 15 to 20% of the poorest in developing countries (Elwan 1999).

Yeo argues that the relationship of chronic poverty with disability and impairment is dependent upon the disabled individual's experience of discrimination from birth (or from time of disablement) which leads to lack of resources, lower expectations, poor health and poor education. In turn, the chronic poverty conditions enhance the risk of illness, injury and impairment, and thus disability (Yeo 2001). It is also clear from several studies that the prevalence of disability is lower in relatively privileged socio-economic groups in both developed and developing countries.

It was argued that poverty was the biggest cause of disability in India because disabled persons were more likely to suffer from malnutrition, live in crowded & unsanitary

conditions (increasing risk of infectious disease) have limited access to medical care, be poorly educated, not immunize their children, lack adequate care during pregnancy and birth and have multiple pregnancies (Parker et al 1994; Melzer et al 2000; Rautio et al 2001; Seeman et al 2001).

A South Indian study (Thomas 2005) was able to demonstrate that disability was found to be more common among the children of families with low monthly incomes. It showed a significant and meaningful relationship with area of residence as an indicator of social status and childhood.

The World Bank reported in 2007 that in India, disability was associated with lower socio-economic status. Survey data from villages in Uttar Pradesh and Tamil Nadu in 2005 showed a clear decline in the proportion of people with disabilities of all severity as the wealth of households rises and a similar pattern could be seen where the measure of disability is by community identification of whether or not a household has a disabled member (Natale et al 1992; World Bank Report 2007).

The financial impact of disablement of a child on the family/household is significant. A recent cross-sectional study conducted in Delhi reveals that loco-motor disability poses a severe socio-economic burden on parents of the disabled children (Laskar et al 2010). More specifically, a south Indian study evaluating the economic burden of families with disabled children indicated that the mean expenditure of the families with a disabled child was high.

Kandamuthan and Kandamuthan (2004) reported that of the disabled children, 80% were not getting any social security payments and 90% had no special concessions for medical and other educational purposes. Of the mothers of the disabled children, 21% were unemployed as against 12% in the case of normal children. Parents of disabled children estimated that they would require, on an average, an additional amount per year as social security payments from the government to meet the essential necessities of their disabled children.

The present study undertaken by Parivaar on the socio-economic status of persons with intellectual and developmental disabilities (PwIDDs) and their families is specific to the status of the most marginalized among the disabled community. This study is not to validate the demographic data of the PwIDDs. It is an attempt to capture the existing conditions under which they live.

In this scenario, Parivaar attempted to undertake this study on the socio-economic status of PwIDDs and their families. When the country is poised to usher in a new legislation based on 'Rights' as enshrined in the United Nations Convention on Rights of Persons with Disabilities (UNCRPD), this study will help us all understand the human rights issue of PwIDDs and their families.

1.1.11 Prediction and Significance of the Study

India has a growing disability rights movement and one of the more progressive policy frameworks in the developing world. But, a lot more needs to be done in implementation and accessing the basics rights. People with disabilities need to be better integrated into society by overcoming stigma; disabled adults need to be empowered with employable skills; both the public and private sector needs to be encouraged to employ them. Persons with disabilities in India need to be better understood by improving the rights situation. Most importantly, persons with disabilities should themselves be made active participants in the development process.

Research in India has consistently found substantial social marginalization of people with disabilities. The attitude of community is critical in assessing both the intensity of disability and areas where collective action is likely to benefit the disabled community. Hence, action on the part of the community is important. In addition to changing the attitudes of the general society, changing the attitudes of persons with disabilities and their families are important and in some ways even more important.

From time to time the government and allied agencies, policy makers, and researchers use information from national surveys for a variety of purposes, including monitoring well-being of the population. However, the existing national disability-related survey and administrative data that are available are limited in their ability to meet the needs of government programs and policy makers. Such limitations include inadequate and inconsistent measures of disability, no data on particular sub-populations of interest, lack of information on specific topics, poor-quality survey data on program participation and service use, and lack of access to and linkages with administrative data.

All available indicators point to the poor quality of life of persons with disabilities and especially intellectual and developmental disabilities and their families. Dr. Amartya Sen candidly describes the plight of people with disabilities when he said: “People with physical or mental disability are not only among the most deprived human beings in the world, they are also, frequently enough, the most neglected.” The PwIDDs are even more marginalized among the disability population due lack of understanding of basic needs.

There are many laws in our country dealing with different subjects. There are different legislations that deal with specific needs of disabilities. In these legislations there are certain provisions meant for the rehabilitation of PwDs. However, these legislations do not ensure their rights. After the ratification of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by India, there is a paradigm change in the outlook o and understanding of the disability issues. Therefore as an obligation, the government of

India has undertaken review of these disability laws and also replace the existing PwD Act of 1995, with a new “Right” based law.

The survey had three components, namely generic demographic data, access to services and personal well-being of PwIDDs. The three components help us understand the situation of PwIDDs and what steps are needed to improve the situation. The findings of the survey will help all persons who are working for the realisation of the UN Convention on the Rights of Persons with Disabilities. The inferences would show a way forward for effective solutions to many problems that affect persons with IDD.

1.2 Methodology

The survey aims to understand the socio-economic status of persons with intellectual and developmental disabilities (PwIDDs) and their families in the country.

1.2.1 Study Objectives

- To study the specific needs of PwIDDs and their families.
- To assess the quality of life of PwIDDs in the family.
- To know the accessibility of various services and their status as individuals in the family and society.

1.2.2 Study Design

Descriptive Study

1.2.3 Selection of the Study Areas

The following states were selected from the region of Northern India, Southern India and Union Territories of India. Moreover the NGOs were chosen to collect the data from the respondents. The details are given below :

*“ T h e
moral test of government is how it
treats those who are in the dawn of life... the
children; those who are in the twilight of life... the
elderly; and those who are in the shadow of life... the
sick... the needy... and the disabled.”*

– Hubert Humphrey

S. No.	States Covered	No. of Organisations Involved	No. of Districts Covered	No. of Sampled Collected	%
South India					
1	Tamil Nadu and Puducherry	14	05	1363	16.60
2	Kerala	06	06	798	9.71
3	Karnataka	13	05	918	11.17
4	Andhra Pradesh	09	07	809	9.85
5	Maharashtra	08	12	1796	21.88
North India					
6	Odisha	11	08	844	10.27
7	Madhya Pradesh	01	01	45	0.55
8	Chhattisgarh	01	01	180	2.19
9	West Bengal	12	06	827	10.07
10	Meghalaya	02	01	182	2.22
11	Goa (UT)	06	05	383	4.66
12	Delhi (UT)	01	01	68	0.83
10 States and 3 UTs		84	58	8213	100

1.2.4 Sampling Procedure

Sample size : 8213 included Male (59.5%) and Female (40.5%)

Sampling method : Purposive method

Universe of the study : People with Intellectual & Development Disabilities PwIDDs

1.2.5 Selection of the Respondents

The following inclusive criteria were followed in the selection of the respondents in this study. Those were:

- Persons with Intellectual and Developmental Disabilities such as autism, cerebral palsy, mental retardation, and multiple disabilities
- The respondents were selected from NGOs intervention areas.
- The States and union territories were selected who have strong network with Parivaar organization

1.2.6 Tools for Data Collection

Survey format

Data Analysis and Interpretation

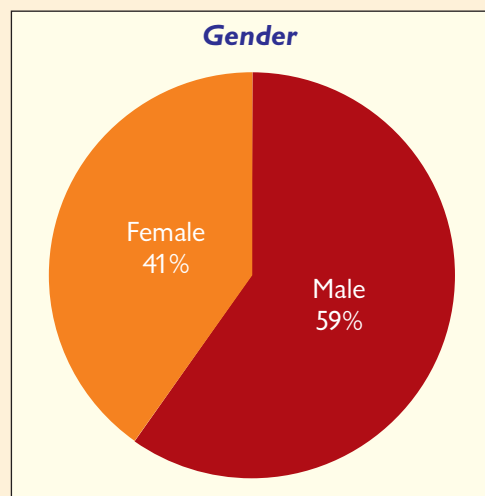
2.1 Age and Gender of the Respondents

Age in years	Male	%	Female	%	Total	%	Group
Below 10 years	1145	13.9	685	8.3	1830	22.3	Children category : 68.3
11 to 20 years	2351	28.6	1429	17.4	3780	46	
21 to 30 years	1010	12.3	801	9.8	1811	22.1	
31 to 40 years	277	3.4	300	3.7	577	7.0	Adult category : 32.7
41 and above	102	1.2	113	1.4	215	2.6	
Total	4885	59.5	3328	40.5	8213	100	

While analysing the age factors of the respondents about 46% of the respondents belonged to age of 11 to 20 years whereas 31.7% of the respondents were under reproductive age (above 20 years) in this study. Children among the respondents were (68.3%) and adult category (32.7%). It indicates IDD's prevalence rate is gradually increasing among children.

2.2 Gender of the Respondents

About 59.5% of the respondents were male and remaining 40.5% female in this study. This data show that the disability prevalence is more among males than females. Another study also reflects (male 54% and female 46%) the same trend. Further, this was in keeping with the general trend as observed in India and elsewhere in the world.



2.3 Educational Status of the Parents

Educational Level	Respondents (N=8213)	Percent	Classification
Illiterate	3407	41.5	Among the parents, Illiterate 41.5% and Literate level 58.5%
Secondary	3171	38.6	
Higher secondary	389	4.7	
UG	457	5.6	
PG	52	0.6	
Professional	351	4.3	
Diploma	386	4.7	

While analysing the educational status of the parents, it was found that about 41.5% were illiterate and 58.5% were literate. The literate parents involve themselves in rehabilitation process of the children.

2.4 Occupational Status of Father

Occupation	Respondents (N=8213)	Percent	Groups
Labour	2268	27.6	37.9% were unorganized sector
Agriculture	848	10.3	
Service	1969	24.0	
Business	1490	18.1	
Others	1207	14.7	
Professionals	266	3.2	
Driver	165	2.0	

About 38% of the parents were from unorganized sector. Their socio-economic condition remains very poor. They are not in a position to utilize the schemes and programs for the benefit of their ward. The table shows that prevalence of disability is among all strata of society.

The only disability in life is a bad attitude.”

- Scott Hamilton

2.5 Community of the Respondents

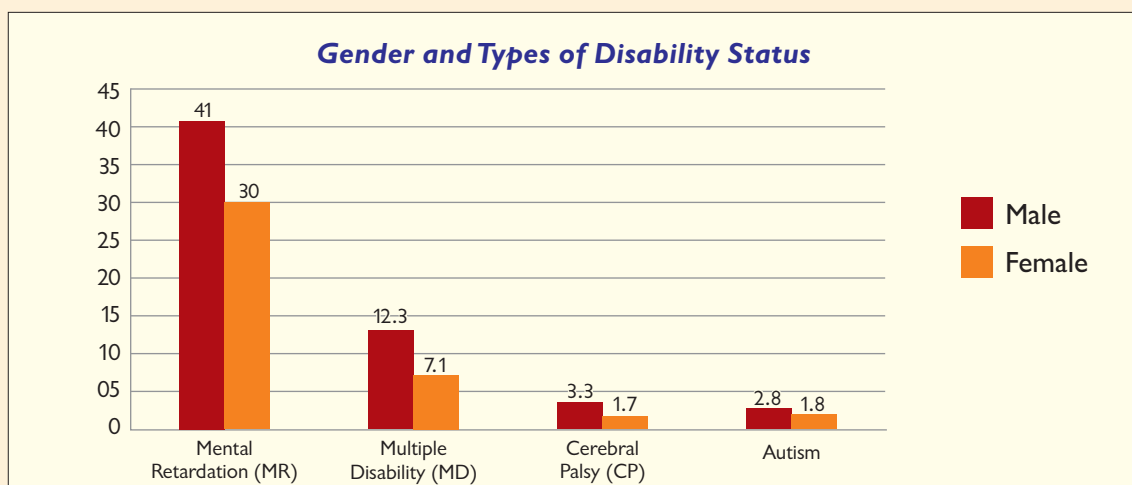
While analysing the community and social status of the respondents, it was found that about 7% of the respondents belonged to minority group of Muslim and Christian. Moreover, 15.3% of the respondents belonged to SC/ST category. In addition, 19.2% were more vulnerable under SC/ST and MBC communities in this study.

Community	Respondents (N=8213)	Percent	Groups
SC/ST	1254	15.3	<ul style="list-style-type: none"> • SC/ST are Most disadvantaged group (19.2%) • MBC and BC are Disadvantaged group (38.6%) • Minority group (14.7%)
MBC	323	3.9	
BC/OBC	1101	13.4	
FC/OC	2070	25.2	
Minority-Muslims	600	7.3	
Minority-Christian	610	7.4	
Not specified	2255	27.5	

2.6 Gender Distribution with Types of Disability

Types of Disability	Male	%	Female	%	Total	%
Mental Retardation (MR)	3371	41	2461	30	5832	71.0
Multiple Disability (MD)	1010	12.3	581	7.1	1591	19.4
Cerebral Palsy (CP)	275	3.3	142	1.7	417	5.1
Autism	229	2.8	144	1.8	373	4.5
Total	4885	59.5	3328	40.5	8213	100

Majority of the respondents (71%) were children and adults with mental retardation (including Down syndrome), multiple disability (19.4%), cerebral palsy (5.1%) and Autism (4.5%).



2.7 Identify Card Facilities among Respondents

Panel	Type of Card / ID	Respondents (N=8213)			
		Yes	%	No	%
I	Disability Identity Card	3227	39.3	4986	60.7
II	Disability Scholarship	1602	19.5	6611	80.5
III	Disability Pension	2158	26.3	6055	73.7
IV	Health Card	2226	27.1	5987	72.9
V	Railway Concession	3265	39.8	4948	60.2

2.7.1 Disability Identity card

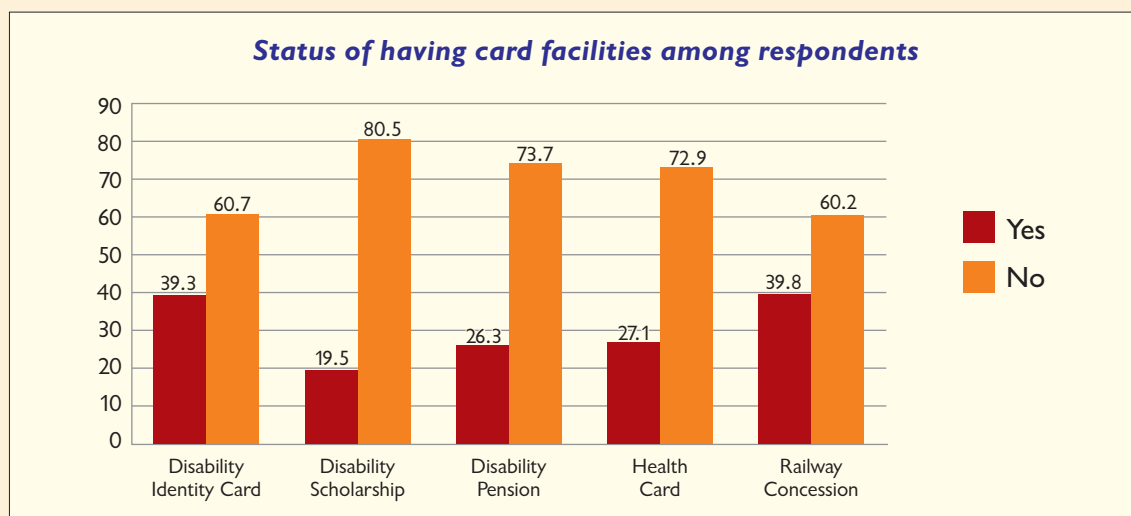
Among the respondents only 39.3% possessed disability identity cards and 60.7% did not have disability identity card.

2.7.2 Disability Scholarship

Under disability scholarship, only 19.5% of the respondents availed scholarship. 80.5% did not avail disability scholarship. The data show the respondents and their families were facing more practical problems in getting disability scholarship from the respective state governments.

2.7.3 Disability Pension

Only 26.3% of the respondents were able to avail disability pension. Remaining 73.7% were not able to avail pension scheme. The disability pension provides support for the disabled person to meet medical emergency and other basic needs. The government departments have to take proactive initiative to distribute the disability pension through proper channel in India.



2.7.4 Health Card (Niramaya)

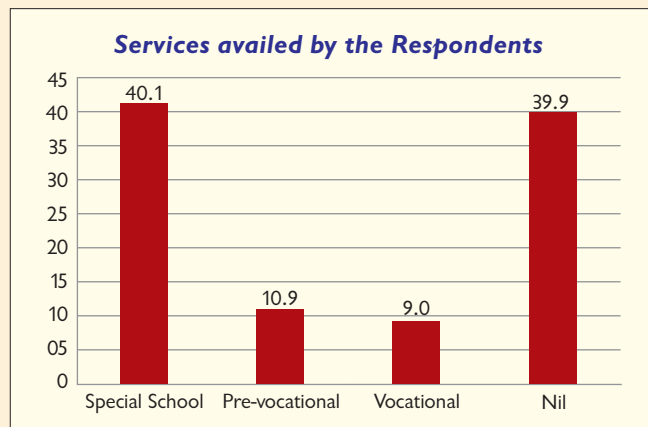
Only 27% of the PwIDDs have access to Niramaya Health Insurance card of the National Trust. This card helps to get health insurance and to meet health care expenses of PwIDDs. The health care is valuable to all PwDs in India, since expenses are increasing day by day for even ordinary illness or common infections. The government, NGOs and other disability organizations have to ensure that PwIDDs have access to Niramaya Health Card.

2.7.5 Railway Concession

About 40% of the respondents were utilizing railway concession facilities and 60% did not utilize this facility. This facility provides PwIDDs more opportunity for mobility than all other PwDs. So, Parents, NGOs, Parent associations should facilitate availing of railway concession facility for all PwIDDs.

2.8 Services Availed by the Respondents

About 40% of the respondents did not avail any services. This may be because of lack of initiatives by the parents, living in remote areas, unable to access the government schemes or not serviced by the government personnel and rigid formalities and procedures in getting government schemes or benefits.



2.9 Guardianship Certificate

The study shows that there were 32.7% adult respondents. Only 9.6% out of the total respondents reported having guardianship certificate. It could be that the awareness, its usefulness has not been felt by parents. Parents

Guardianship Certificate	Respondents (N=8213)	Percent
Yes	786	9.6
No	7427	90.4

of PwIDDs are still unaware of the facility provided by National Trust. The guardianship certificate is a very important instrument for adults with IDD to get benefits and access to rehabilitation schemes from the government sector.

2.10 Gender and Income Category

Family Income Category	Male	%	Female	%	Total	%
Below Poverty Line	2290	27.9	1740	21.2	4030	49.1
Above Poverty Line	2595	31.6	1588	19.3	4183	50.9
Total	4885	59.5	3328	40.5	8213	100

Nearly half of the respondents (49%) were under below poverty line category whereas 51% were under non poverty line category in this study. So there is need for further explorative study on the BPL category of PWIDDs. The burden of spending more money, time and energy for their disabled children adds to the poverty of the family. Due to this, more families are pushed to BPL category.

2.11 Access to Aids/Appliances

Among the respondents only 32% availed aids and appliances from the government sector. The need for aids & appliances may not be felt by PwIDDs and therefore 68% may not have availed the opportunity to get aids and appliances.

Aids/Appliances availed	Respondents (N=8213)	Percent
Yes	2630	32.0
No	5583	68.0

There is no real effort to identify the aids and appliances needed by PwIDDs. The government schemes and programs have not reached grass root level for the disabled people in India.

2.12 Relationship of the Guardian to the Respondents

The National Trust Act emphasizes the importance of the guardianship for the adults with IDD in India. In about 80% of the cases, father was the most preferred 'guardian', followed by mother in the second position (15.2%) and others (4.2%).

Relationship with Guardian	Respondents (N=8213)	Percent
Father	6620	80.6
Mother	1247	15.2
Others	346	4.2

2.13 Marital Status of PwIDD

In response to the marital status of PwIDDs only 37 were married. Families have not really thought of Social relationships for their PwIDDs. Even if the need was felt, it may have been ignored as it adds to the burden on the family.

Marital Status	Respondents (N=8213)	Percent
Married	37	0.5
Unmarried	8176	99.5

2.14 Siblings

Siblings	Respondents (N=8213)	Percent	No. of Siblings	Respondents	Percent
Male	1842	22.4	one	2971	36.2
Female	1828	22.3	Two	1515	18.4
Both	1651	20.1	> 2	836	10.2
None	2892	35.2	None	2891	35.2

While analyzing the status of siblings about 65% responded having either one or two siblings in the family. There are also a significant percentage of respondents who do not have siblings (35.4%). The siblings play an important role in the lives of other siblings and their presence is vital during the crisis period of PwIDDs. The siblings provide not only personal care but also are role models and help in the personality development of the PwIDDs.

2.15 Minority Group / Community among the Respondents

Among the total respondents there were 7.3% Muslim and 7.4% Christian (7.4%). About 14.7% respondents belong to minority group in India.

Minority Group	Respondents (N=8213)	Percent
Muslims	600	7.3
Christian	610	7.4
Total	1210	14.7

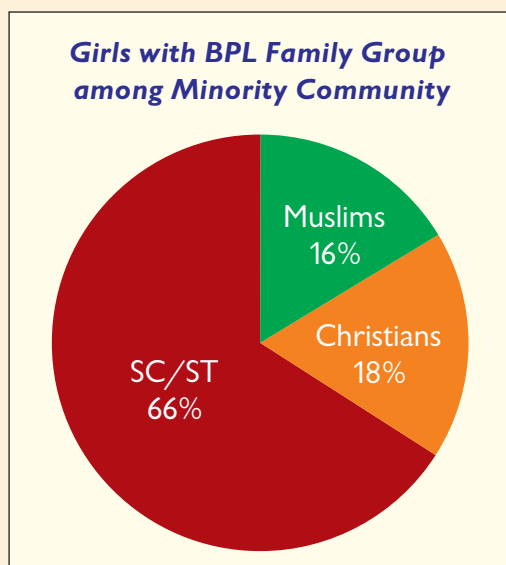
2.16 Female Adult with Vulnerability

Age Group (Adult Group)	Girls with SC/ST Community		Girls with BPL Family	
	Female (N=3328)	Percent	Female (N=3328)	Percent
11 to 20 years	254	7.6	777	23.3
21 to 30 years	99	3.0	387	11.6
31 to 40 years	27	0.8	120	3.6
41 and above	5	0.1	57	1.7
Total	385	11.5	1341	40.2

While analysing the female adult's status, about 11.5% were SC/ST category and 40.2% were under BPL category. The above groups are more vulnerable in getting physical care from the family. They are discriminated sexually.

2.17 Girls/Women in BPL Category in Minority Community

The chart below indicates that there are more downtrodden respondents among female respondents in this study. About 17% of the respondents were under BPL category in the minority community. Needless to say, families with these women with IDD face more problems than any other.



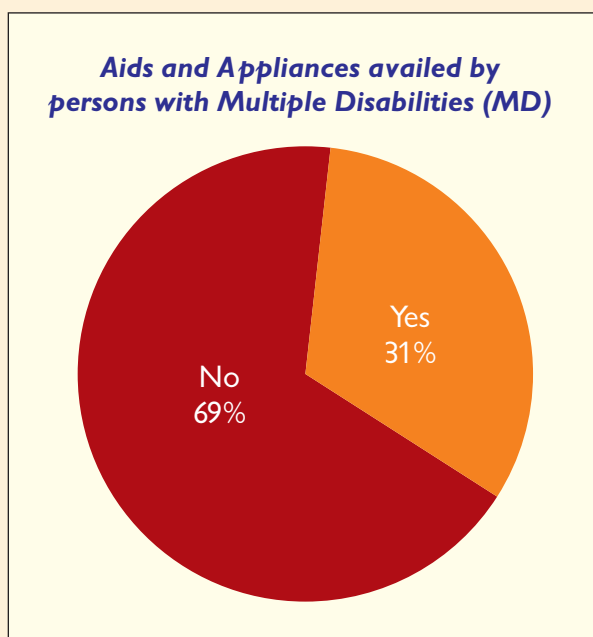
2.18 PwIDDs among BPL families having single parent

Single Parent Category	Male (N=4885)	%	Female (N=3328)	%	Total	%
Mother	338	14.8	219	12.6	557	27.4
Others	113	2.8	78	1.9	191	4.7
Total	451	17.6	297	14.5	748	32.1

Among the respondents of PWIDDs with BPL families having single parent totally 32% were having single parents with support of mother (27.4%) and others (4.7%). The respondents of the single parent are more vulnerable. The mother has a dual role of bread winner and care giver in the family. So the BPL category families and PWIDDs have more livelihood needs. The survey indicates that about (3.6%) particularly female respondents are more vulnerable among PwIDDs. They live with single parent mostly with mother and/or others. Single parents face many hurdles and the responsibility of managing the family. There is a need for ensuring the programs and schemes of the government to reach these needy women with IDD.

2.19 Status of Aids and Appliances availed by persons with Multiple Disability

Among the multiple disabled respondents, only 31% could avail aids and appliances from the government department and 69% did not have access to the aids and appliances provided by the government sector. The data analysis shows that the services are not reaching persons with multiple disabilities properly. Another study reported that with regard to aids and appliances, 89.5% did not use any aids and appliances. This shows that really needy disabled persons did not receive the aids and appliances.



Chapter III

Results and Discussion, Suggestions and Conclusion

Age and Gender:

Majority of the respondents (46%) age of 11-20 years whereas 31.7% were under reproductive age (>20 years) in this study. Children among the respondents were (68.3%) and adult category (32.7%). It indicates IDD's prevalence rate is gradually increasing among children. About 59.5% of the respondents were male and remaining 40.5% female in this study. This data show that the disability prevalence is more among males than female. Further, this was in keeping with the general trend as observed in India.

Educational Status of the Parents:

About 41.5% of parents were illiterate and 58.5% were literate. The literate parents encourage their children in rehabilitation process socially and psychologically.

Occupational Status of Father:

About 38% of the parents were from unorganized sector. Their socio-economic condition status remains very poor. They are not in a position to utilize the schemes and programs for the benefit of their ward. The table shows that prevalence of disability is among all strata of society.

Community of the Respondents:

About 7% of the respondents belonged to minority group of Muslim and Christian. Moreover, 15.3% of the respondents belonged to SC/ST category. In addition that 19.2% were more vulnerable under SC/ST and MBC communities in this study.

Types of Disability:

Majority of the respondents (71%) were having mental retardation (including Down syndrome) under MR category, multiple disability (19.4%), cerebral palsy (5.1%) and Autism (4.5%).

Disability Identity card:

Among the respondents only 39.3% possessed disability identity cards and 60.7% did not have disability identity card.

Disability Scholarship:

Under disability scholarship, only 19.5% of the respondents availed scholarship. 80.5% did not avail disability scholarship. The data show the respondents and their families were facing more practical problems in getting disability scholarship from the respective state governments.

Disability Pension:

Only 26.3% of the respondents were able to avail disability pension. Remaining 73.7% were not able to avail pension scheme. The disability pension provides support for the disabled person to meet medical emergency and other basic needs. The government departments have to take proactive initiative to distribute the disability pension through proper channel in India.

Health Card (Nirmaya):

Only 27% of the PwIDDs have access to Niramaya Health Insurance card of the National Trust. This card helps to get health insurance and to meet health care expenses of PwIDDs. The health care is essential to all PwDs in India, since expenses are increasing day by day for even ordinary illness or common infections. The government, DPOs and other related organizations have to ensure that PwIDDs have access to Niramaya Health Card.

Railway Concession:

About 40% of the respondents were utilizing railway concession facilities and 60% did not utilize this facility. This facility provides PwIDDs more opportunity for mobility than other PwDs. So, Parents, NGOs, Parent associations should facilitate availing railway concession facility for all PwIDDs in India.

Services Availed by the Respondents:

About 40% of the respondents did not avail any services. This may be because of lack of initiatives by the parents, living in remote areas, unable to access the government schemes or not serviced by the government personnel and rigid formalities and procedures in getting government schemes or benefits.

Guardianship Certificate:

The study shows that there were 32.7% adult respondents. Only 9.6% out of the total respondents reported having guardianship certificate. It could be that the awareness, its usefulness has not been felt by parents. Parents of PwIDDs are still unaware of the facility provided by National Trust. The guardianship certificate is a very important instrument for adults with IDD to get benefits and access to rehabilitation schemes from the government sector. Besides, The National Trust Act makes it to provide social security of the PWIDDs in India.

Gender and Income Category:

Nearly half of the respondents (49%) were under below poverty line category whereas 51% were under non poverty line category in this study. So there is need for further explorative study on the BPL category of PWIDDs. The burden of spending more money, time and energy for their disabled children adds to the poverty of the family. Due to this, more families are pushed to BPL category.

Access to Aids/Appliances:

Only 32% availed aids and appliances from the government sector. The need for aids & appliances may not be felt by PwIDDs and therefore 68% may not have availed the opportunity to get aids and appliances. There is no real effort to identify the aids and appliances needed by PwIDDs. The government schemes and programs have not reached grass root level for the disabled people in India.

Relationship of the Guardian to the Respondents:

The National Trust Act emphasizes the importance of the guardianship for the adults with IDDs in India. In about 80% of the cases, father was the most preferred 'guardian', followed by mother in the second position (15.2%) and others (4.2%).

Marital Status of PwIDD:

In response to the marital status of PwIDDs only 37 were married. Families have not really thought of Social relationships for their PwIDDs. Even if the need was felt, it may have been ignored as it adds to the burden on the family.

Siblings:

About 65% responded having either one or two siblings in the family. There are also a significant percentage of respondents who do not have siblings (35.4%). The siblings play an important role in the lives of other siblings and their presence is vital during the crisis period of PwIDDs. The siblings provide not only personal care but also are role models and help in the personality development of the PwIDDs.

Minority Group / Community among the Respondents:

Among the total respondents there were 7.3% Muslim and 7.4% Christian (7.4%). About 14.7% respondents belong to minority group in India.

Female Adult with Vulnerability:

About 11.5% were SC/ST category and 40.2% were under BPL category. The above groups are more vulnerable in getting physical care from the family. They are discriminated sexually.

Girls/Women in BPL Category in Minority Community:

About 17% of the respondents were under BPL category in the minority community. Families with these women with IDD face more problems in managing at home.

PwIDDs among BPL families having single parent:

Among the respondents of PWIDDs with BPL families having single parent totally 32% were having single parents with support of mother (27.4%) and others (4.7%). The respondents of the single parent are more vulnerable. So the BPL category families and PWIDDs have more livelihood needs. The survey indicates that about (3.6%) particularly female respondents are more vulnerable among PwIDDs. They live with single parent mostly with mother and/or others. Single parents face many hurdles and the responsibility of managing the family. There is a need for ensuring the programs and schemes of the government reach these needy women with IDD.

Multiple Disabled (MD) availed aids and appliances:

Among the multiple disabled respondents, only 31% could avail aids and appliances from the government department and 69% did not have access to the aids and appliances provided by the government sector. This shows that really needy disabled persons did not receive the aids and appliances.

Conclusion:

The study reveals that PwIDDs and their families are extremely marginalized in all aspects of life. Therefore,

- There is a need to give greater emphasis for the development of persons with PwIDDs.
- Awareness raising among parents on the importance of early identification and intervention of IDDs.
- The quality, timely services and facilities are needed to get government scheme like Niramaya health card, railway concession, and national identity card and so on.

- There is an urgent need to promote effective policy and scheme implementation system related to IDD in India.
- Empowering PwIDDs are essential in way of early identification, imparting scientific training based on the classification of IDD in India.
- Skill development is one of the vital requirements in PwIDDs for the independence of their social functioning.
- Repetitive skill development training is needed for social behaviour of PwIDDs.
- There is a need to create awareness among policy makers and program implementers on every developmental programs aimed for better social functioning for the development of PwIDDs in India.
- Education, inclusive education and service training are the fundamental requirement for empowering PwIDDs and it should be reached to unreached areas in India.
- One of the priority areas that the government should concentrate is on the schemes for the welfare of PwIDDs.
- Strengthening of SSA scheme is needed to enhance the quality of inclusive education.
- Poverty and Disability go hand in hand. The capacity building, social security and sustainable livelihood programs are to be properly implemented for them.
- Need self help organization of PwIDDs at community level to Escalate the issues to the local/district/State and National Level for effective advocacy.
- Create barrier free or user friendly environment at school level/Therapy centre and Vocational centre for easy accessibility of PwIDDs.
- Adequate vocational skills have to be developed to sustain their social functioning in the life.
- Adequate life-skills have to be promoted enrich the day today activities of PwIDDs.
- The parents have to be involved in program planning and overall development of the children with IDD in India.
- Create positive attitude and right perspective in the community to accept the welfare of PwIDDs as social responsibility.
- The declaration and national acts are emphasizing the need for services to PwIDDs. These would be in the version from charity to rights based approach for the welfare of the PwIDDs.
- A comprehensive mainstream strategic planning is needed in the field of education, training and employment for PwIDDs.

- There is a need for multi-disciplinary approach for developing the persons / children with multiple disabilities.
- Special awareness sessions to be conducted for young parents for identifying the children who have non-observable disability conditions.
- Under SSA, there is a need to strengthen the cognitive skills of PwIDDs at school level.
- Ability based approach and society based approach are needed to face emotional balance and its related problems among PwIDDs.
- To create attitude change among general public to recognize the abilities and status of PwIDDs.
- Early identification and intervention are paramount importance in the life of every PwIDDs. The research study indicated that early identification and intervention provided integration with family and community in a larger extent.

“Being disabled should not mean being disqualified from having access to every aspect of life.

- Emma Thompson

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Annexure

Introduction and activities of PARIVAAR

PARIVAAR is a grass - root level organization formed in 1995. It is a confederation of over 230 Parents Associations and NGOs in 30 States and Union Territory of India and working for Persons with Intellectual and Developmental Disabilities (PwIDDs). It is a National Confederation of Parents' Organizations for persons with intellectual and developmental disabilities (NCPO).

Vision: To empower, secure rights and improve the quality of life of Persons with Intellectual and Developmental Disabilities and their families in the country.

Mission: Creating awareness in the community for inclusion of Persons with Intellectual and developmental Disabilities (PwIDDs) as contributing citizens at par with others, through advocacy, lobbying, creating inclusive environment and building a common platform by joining hands with all deprived sections of the society.

Objectives

- To secure legal rights for persons with mental retardation, cerebral palsy, autism and multiple disabilities and their families;
- To fight for human rights and social justice, against exploitation, abuse and discrimination by implementation of legal rights of persons with these disabilities and by appropriate representation for PARIVAAR-NCPO in policy making and implementation bodies at Central, State and at local level;
- To promote interests of persons with mental retardation, autism, cerebral palsy and multiple disabilities and their families by bringing about cooperation and coordination among organizations at State/District level;
- To endeavor for bringing about inclusion of the disabled in all fields of life with the focus on inclusive education; to create common bond of understanding and action among parents, families, professionals and others concerned with the problems of the above disabilities, throughout India and the world;
- To protect all rights of persons with disabilities and their parents, families, guardians and enabling them to live a life of dignity and enjoy full citizenship rights;

- To endeavor to bring all parents under the common umbrella of PARIVAAR-NCPO, by forming Parents' Associations and train them to function as pressure groups to achieve the above objectives and to create public awareness through print and electronic media and through all other means.

Role of Parivaar in campaigning and lobbying

Since its inception, PARIVAAR has established its credibility with the Governments at the National & State level and in international forums. It is the only apex organization at the national level that speaks for the rights of persons with intellectual and developmental disabilities (PwIDDs) and their families. PARIVAAR ceaselessly fights for job reservation, proper and effective implementation of all legislations and programs of the central and state Governments through representation, lobbying and direct action.

Parivaar was a Member of Drafting Committee to replace PwD Act of 1995 constituted by Government of India. The bill is called Rights of Persons with Disabilities Bill 2011 and it is yet to be passed by the Parliament.

PARIVAAR continues to lead the parents and PwIDDs in the country as a united cohesive organization and provide assistance through its network of parents' associations.

Parivaar's Networking Activities in India

Parivaar is a full member of the Inclusion International, a world body of parents' Associations of above disabilities in over 200 countries closely working with UN and its agencies. PARIVAAR has been taking various initiatives for the benefit of its member associations and other DPOs.

In an ongoing partnership with CBM, South Asia Regional office, we undertake capacity building and leadership training; Promote self-advocacy among persons with PwIDDs and have established seven Self Advocacy Forum of India (SAFI) chapters in seven states; promote formation of Self-help-groups among parents and PwIDDs for providing occupation and employment through micro-economic activities. Over 500 SHGs have been formed and functioning in 7 states.

Parivaar conducts Parents' awareness workshops at district & local level; builds network of parents' organizations at state and facilitated formation of legally constituted State Federations in seven states of India for stronger state level advocacy role; works with cross-disability organizations. It created Cross-disability Alliance in the state of Andhra Pradesh.

Collaborative Activities of Parivaar

Annually conducts 10 Regional and one National parents' meets throughout India in collaboration with National Institute for the Mentally Handicapped (NIMH); conducted first partnership workshop for persons with multiple disabilities at Guwahati in collaboration with National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), both autonomous bodies under the Ministry of Social Justice & Empowerment. Recently, held a cross disability workshop in collaboration with National Institute for Rural Development (NIRD), Government of India. This collaboration will specifically focus on including disability perspective in the development of program for rural sector under the ministry of Rural Development. The disabled population in the entire country may benefit from this collaboration.

IEC activities

Parivaar brings out quarterly Newsletter and awareness material; supports initiatives for Inclusive Education policy of the government and counsels, advises and helps the affiliated organizations and individual Parents.

As a member of Inclusion International, Parivaar participated in the Asia-pacific Regional Forum meeting in advancing UNCRPD in the region

Research Activities

Parivaar conducted a research study on the quality of life of persons with Intellectual and developmental disabilities in India with assistance from SIDA, Sweden.

Parivaar undertook Demonstration projects on Supported Decision Making in Dehradun, Bangalore, Bhilai, Bhubaneswar, Hyderabad, Delhi and the next one is scheduled to be undertaken in two districts in Kerala in 2012 with support from DRF, USA.

Parivaar, as a lead organization is involved in National Coalition project titled "Hear Our Voices" in monitoring and reporting on the rights of PwDs living in rural Communities of India as enshrined in UNCRPD with support from DRF, USA.

This Socio-economic research study of PwIDDs and their families is supported by AusAID and CBM South Asia Regional Office, Bangalore.

*"ATTITUDE IS THE
BIGGEST BARRIER FOR INCLUSION OF
PERSONS WITH DISABILITY IN THE
COMMUNITY"*

Glossary

ARUNIM	- Association for Rehabilitation Under National Trust Initiative of Marketing
CBS	- Community Based Scheme
CP	- Cerebral Palsy
DFID	- Department For International Development
GHARAUNDA	- Group Home And Rehabilitation Activities Under National Trust Act for Disabled Adults
HDI	- Human Development Index
IDDs	- Intellectual Developmental Disability
MD	- Multiple Disabilities
MR	- Mental Retardation / Mentally Retarded
NGO	- Non Governmental Organization
NSSO	- National Sample Survey Organization
PDD	- Pervasive Developmental Disorder
PwDs	- Persons with Disability
PwIDDs	- Persons with Intellectual and Developmental Disability
RCI	- Rehabilitation Council of India
SSA	- Sarva Sikhsha Abhiyan
UNCRPD	- United Nations Convention on Rights of Persons with Disabilities
UT	- Union Territory