Report on Existing Circle of Support for Autistic & Disabled Children in Rural Area

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Preface

To be born in to rural poverty in India is to begin life with a handicap for it often means a helpless and stoic acceptance of a variety of social ill, hunger, disease, squalor, illiteracy and a daily battle for the basic necessities of life. In addition if a poor person is born with, or due to some unfortunate circumstances acquires a disability then he or she must face life with double handicap. Hence every problem that confronts the able bodied, afflicts the disable person in a more intense & chronic form.

The rural Persons with Disabilities (PWD) are at a disadvantage when compared to their access to resources, employment opportunities & rehabilitation. They are usually denied education and the right to enjoy normal social interaction and relationship. The employment opportunities for the uneducated and untrained disabled are so limited that the PWD is considered a burden on his / her family. Almost 70 to 80 % of Indians with disabilities live in rural areas and the great concern of this community is that mostly these prevalence of rural PWDs comprised of help less young children who are deprived of rehabilitation service as because rehabilitation centers are situated in urban areas. To transport the disable persons to these centers for diagnosis, treatment, or training is an expensive process, involving not only the cost of the travel but also the loss of daily wage of the escort. India for instance has nearly 100 million disable persons.
For presentation the text of this report is divided in to 5 chapters. The first chapter projects the scenario of disability in India with special reference to rural areas. The acts safeguarding the rights, provision and facilities for the disable by the government and the non-government agencies, family dynamics, various types of disabilities, its category etc are explained in this corresponding chapter.

The second chapter highlights the organization's profile under whose support the report was prepared. The chapter also depicts about area and people where the project work had been carried out by the investigators.

The third chapter includes the description of the methodology used for data collection by the investigators and tabulation of data.

The fourth chapter includes discussion, analysis, and interpretation of data.

The fifth chapter includes the summary of the findings and relevant recommendation which has been extracted form the community during the course of the study.

Acknowledgement

This report would not have been possible without the help and support of team of guide and interpreters. But it is difficult to carry out our wishes to all of them hence the below mentioned list may appear partial. We would express our heartfelt wishes to all of them whoever have encouraged, supported & guided us to bring this report in this present form.

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(Rajula Ekka) (Manish Bijalwan)

Date- Date-

Chapter- I

Introduction

The concept of disability varies from society to society because the attitudes towards disability are deeply rooted in the socio cultural values and disability has been defined in different ways. The disables are the victims of mental and physical harassment, discrimination, vigilance of over protection, and dependency. Besides other terms like impairment and handicaps are synonymous and are used for defining disability .The World Health Organization (WHO) has defined disability in the following way

Disability: Disability is considered to be any loss of ability of any individual that makes him functionless partially or completely.

The model of the circle Of Support (COS) was introduced in the western countries in the eighties which spread out very quickly to other parts of the globe with the realization of its implication upon the persons with disabilities, who are neglected by the society most often. In western countries as well as in India currently the PWDs are in a state of social exclusion due to very high level of preoccupations, materialistic outlook of people, disintegration of joint families etc. Government policies & various Acts for safeguarding rights of PWDs call for the equal opportunities, full social and economic participation and empowerment of the differently abled persons. But the process of the social change places the communities under severe tensions to implement the appropriate policies for PWDs. There are varying degrees of disintegrative pressures on the social cohesion in countries. In such circumstances the most vulnerable members of the society come under the threat of exclusion. Hence recently has been felt to strengthen the informal support networks in the local communities for a better care of the PWDs. Strengthening the informal support networks in the society targets the empowerment of their members for the social inclusion PWDs in the most comprehensive manner. The idea of COS has thus emerged as an important approach in this context.

The Circle of Support is a group of people who meet together regularly to help a disable; individually accomplish his / her personal goals in life which is not achieved by him / her independently. The members of Circle of Support may include a facilitator, family, friends, other community members and institutions. A circle properly facilitates to empower all of the individuals involved and does not reinforce dependence. A circle can support a person in every matter, in working life and in social relations.

There is a lot of truth in the statement that the birth of a disabled child makes the entire family handicapped. The parents are seldom prepared not to have a perfectly healthy child. They await the infant's arrival for nine months. Their distress at the discovery of disability in their beloved child is understandable. It could be reduced by timely help of rehabilitation & counseling, although the scars of this experience for the family always remain. A majority of disabled people born with disabilities or acquire disabilities in their early years. The parents and other members of the family realize that something has gone wrong but either find it difficult to express their concerns or ask the right questions to people who do not know. In most cases the news about their child's disability is broken to them in a most unsympathetic manner. There are seldom day care facilities or long-term residential arrangement available is

available in rural area for the children with severe or profound category of disabilities. Even if correct and precise diagnosis is made the families are not given any advice on how to look after the infant in even routine matters. They run from one doctor to another and from one specialist to the next without any precise understanding of their child's problems, the things he / she can or can not do. The reactions of the families of those who become disabled in later years of their lives as a result of an accident or a disease are no less serious than those of the parents of children born disabled. Their situation perhaps is still worse.

A sudden onset of disability in the family shatters the normal family relationships and frequently the stress caused by disability is too much not only for the person with the disability but for all others related to him / her. They and those who care for them have to pay for services that they had never thought would be needed. The demand for making adjustment to the new situation is often too shocking or depressing. The relatives feel a deep sense of embarrassment and start to withdraw from social contacts and social gatherings. If the person has been married then not only the parents and siblings but also the spouse and children need a lot of advice and counseling so that they, in turn, may be able to offer support to the disabled member of the family. Frequently, there is no one to give them correct information about the rehabilitative services available and how to cope with daily problems. The elderly disabled, wooing to their age and their disability, face enormous problems of self-care, cooking and mobility; shrinking net of social relationships and substantial expenses to bear when their incomes start declining

The difficulties and distress of these families need not have been as enormous as they have been. Their problems of finance, unsuitable housing, extreme difficulties in mobility for the disabled member, inadequate health and social services, absence of relevant information about the disabling condition and the ways of managing it could be minimized by society and its various agencies. In the interest of long-term and comprehensive rehabilitation, children could be provided with education, those educated with vocational training and then suitable jobs, adequate housing, facilities for public transport and recreation so that the burden put on families gets reduced to manageable, dimensions. Without such constant and visible practical support, the interpersonal relationships within a family remain fragile because of the enormous task of looking after their disabled member is results into absolute stress.

During the last two decades, in most countries of the world there has been a growing realization that institutional care for the disabled, as well as for other groups requiring long-term residential services, is not entirely suitable for their individual needs, dignity and independence. A number of governments have actually succeeded in achieving noticeable reduction in the numbers of in-patients in institutions and have managed to send them out into communities which do not have adequate provision of services and facilities. Another new concept of providing support to the persons with disabilities is the Community Based Rehabilitation or the CBR.

CBR is a process of motivating and providing inputs-which could be medical, technical or social-to the community to take care of its disabled. To put it very simply, it is a system of enabling the disabled in their community and through their community.

Dr. Helander one of the prime movers in the rehabilitation field and the co author of the world health organization's landmark manual. "Training with community for the PWDS" has opined as "the prerequisites for CBR is to become a reality have been described as full and coordinated involvement of all levels of society and integration of the interventions of all relevant sectors- education, health, legislative, social and vocational, and aims at full representation as well as empowerment of disabled people". Helander goes on to describe the aims of CBR including adaptation of the physical and psychological environment that will facilitate the social integration and the self actualization of disabled people. Its goal is to bring about a change, to develop a system capable of reaching all disabled people in need and to educate and involve governments and the public. At the community level the CBR is seen as the component of integrated community development programme. It should be based on the decisions taken by its members and it will rely as much as on the mobilization of the local resources the family of disabled person is the most important resource. Its skills and knowledge should be promoted by adequate training and supervision. Using a technology closely related to the local experience the community should support the basic necessities of life and help the family who carry out rehabilitation at home. CBR focuses on all local opportunities for educational function and vocational training jobs etc for the PWDs. The community is facilitated to protect its disabled members and their families are involved in all discussions and decisions regarding service and opportunities provided for PWDs. Under general consensus of community one or more of its member are selected to undergo training in order to implement the programmes. Under CBR community structure is promoted for managing the local rehabilitation committee. At the intermediate level the professional support should be involved in the training. Technical supervision of the community personnel are also availed for service delivery, managerial support & to liaise with the referral service centers. Referral services are needed to receive those disabled people who need more specialized intervention than the community can provide. The CBR system generally draws on the resources both on the government and the non government sector including organization of disabled persons.

The subject of the role of media and disability attracts more opinions than understanding. Most of the discussion is about merits or demerits of an irrelevant issue and not about the social system and its total impact on society. Media contributions, if well coordinated and well intentioned, have the potential to create a caring society. All forms of media must show a healthy respect for this new situation and take advantage of it for and with people with disabilities. At present there are possibilities for any people in any part of the country to install an improved direct-to-home satellite system offering 150 high-quality TV channels through dinner-plate sized dishes. Flow of information on disability issues and their solutions and on many other topics of shared interest and opportunities for collective action will flow easily, across the borders, and bring disabled people form all over the world to get united to demand and get their rights. Exchange of information will play lead role in restoring dignity of disabled people and for creating a new sense of international comradeship which transforms societies.

Much of disabled people's well-being, the fullness of their participation in the mainstream activities of society and their victory in eliminating discriminatory practices depend on the use of efficient dissemination of correct, valid and relevant information, in formats that they can use.

Concepts of disability

As per the person with disability (Equal Opportunities, Protection of right and full participation) act 1995

Disability means:

- Blindness
- Low Vision
- Leprosy Cured
- Hearing Impairment
- Locomotors Disability
- Mental Retardations
- Mental Illness

1) **"Blindness"**

   Blindness refers to a condition where a person suffers form any of the following condition, namely

   a) Absence of sights
   b) Visual impairment not exceeding 6/60 or 20/200 (snellen)
   c) Limitation of the field of vision subtending an angle of 20 degrees or worse;

2) **"Low Vision"**

   Person with low vision means of person with impairment of visual functioning even after treatment or standard refractive correction but who uses or is potentially capable of using vision for the planning and execution of a task with appropriate assistive device.

3) **"Leprosy Cured"**

   Leprosy cured means any person who has been cured of leprosy but is suffering form

   a) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eyelid but with no manifest deformity
   b) Manifest deformity and paresis but having sufficient mobility in their hands and fetes. To enable them to engage in normal economic activity.
   c) Extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation and the expression "Leprosy Cured shall be constituted accordingly"

4) **"Hearing Impairment"**

   Hearing Impairment means loss of 60 decibels or more in the better ear in the conversational range of frequencies.

5) **"Locomotors Disability"**

   Locomotors Disability means disability of bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy. ***"Cerebral Palsy"*** means a group of non progressive conditions of person characterized by abnormal motor control posture resulting from brain insult or injuries occurring in the pre-natal, peri-natal or infant period of development.

Cerebral Palsy (CP) may be the result of irreversible damage to one or more concerned areas of brain, during intrauterine life, labor or infancy. A particularly vulnerable part is the Internal Capsule region of brain where most nerve fibers from the muscle controlling areas of brain come together to then pass down to the spinal cord. This area has the poorest blood supply and is the most frequent site of blood flow obstructive disorders, even in adult life. Nerve fibers from the muscle controlling areas of brain come down and bunch together at a place called internal capsule. This area is notorious for its poor blood supply and is almost always the victim of any deficiency in blood supply, both in infants and adults. This leads to paralysis of muscles controlled by those nerve fibers. In cerebral palsy caused by low blood supply injury, this is a common site of injury.

6) "Mental Retardation"

Mental Retardations mean a condition of arrested or incomplete development of mind of person which is specially characterized by sub-normality of intelligence.

7) "Mental Illness"

Mental Illness means any mental disorder other than mental retardation.

8) Multiple Disabilities

About 80% of people with disabilities are in the rural areas. Parkinson's disease, Leprosy, Loss of sensation and other physical impairments are included here as forms of disability

As per the PWD Act. 1995 of person with disability is one who suffering from not less than 40% of any disability certified by the medical authority.

Autism:

Autism is a disorder of the brain that causes a lifelong development disability, primarily affecting the communication and social abilities of people. Symptoms of the condition are evident either from birth or may appear after a period of normal development, but definitely by the time the child is two and a half years old. It typically affects / or is noticed in the infant and toddler stages and many symptoms may remain for life.

Autism is known as a 'spectrum disorder', because the severity of symptoms ranges from a mild learning and social disability to a severe impairment, with multiple problems and highly unusual behavior. A spectrum disorder is one in which each individual with the disorder may present a varying combination of symptoms from a set of defined behaviors. Two people with autism may not exhibit the same characteristics. The disorder can range from the mild to severe. The disorder may occur alone, or with accompanying problems such as mental retardation or seizures. Autism is nor a rare disorder, being the third most common developmental disorder, more common than Down's syndrome. Typically, about 20 in a population of 10,000 people will be autistic or have autistic symptoms. 80% of those affected by autism are boys. Autism is found throughout the world, in families of all economic, social, and racial backgrounds. Doctors, politicians, and rickshaw drivers a like all have autistic children.

Other similar disorders are Asperger's disorder, Pervasive Developmental Disorder, Rett's Disorder,Childhood Disintegration disorder etc.

Causes of Disability:

With reference to past researches it is indicated that disability around the society stems out from certain factors like psychological, biological, and environmental. In some instances disable do suffer for their past psychological dynamism. Mostly their parents are illiterate who don't train and guide their children in a desirable manner like controlling their negative emotions like aggression, frustration, agitation etc. In some cases they even deal with their children very antagonistically which deteriorate their emotional state. Another etiological background behind their disabilities is belonging from pathogenic family background or broken families like separated parents or divorced parents. In addition they are illiterate & they don't know to read & write. This indicates that the reasoning & cognitive power is below average or normal. This does not help them to control their behavioral at the crisis state. Even poor parental training makes them more dependent. As a matter of fact their decision making ability becomes poor & irregular. They with respect to their psychopathic condition become acutely ill.

Secondly, we come across to the biological dynamics which indicates that some of the disables become the victim of it for their biological conditions like faulty heredity, gene predisposition, prenatal, postnatal infections, infectious diseases like measles, chickenpox etc. and certain vitamin deficiency disorder like whooping cough, beriberi, polio, diphtheria, etc. The recurrent infectious diseases, presence of endemic diseases also add to the factors responsible for disability. The low-health and nutritional status of both the mother and the baby can be other additional factors. The lack of indispensable immunization of the mother and the baby & lack of periodical checkups are also causes of disability.

Thirdly there are certain environmental conditions which to certain extent act as an impinging force for generating disability around the community. The physical environment of the locality as such is not safe. Accidents, slum privations, pavement dwelling may also lead to disability. Presence of taboos, customs & traditional practices also add to the disability.

CAUSES FOR DIFFERENT TYPES OF DISABILITY

To go on the particular causes of the most common types of disabilities it is explained herewith separately. The following factors are associated for the occurrence to lead different type of disability. These are Malnutrition, Diseases, accidental and trauma, Genetic, Pregnancy and Obstetric related problems

Visual Impairment;

- Vitamin A deficiency
- Infection in eye
- Use of unhygienic water or cloth
- Diseases
- Accidental
- Abnormal pregnancy

Speech and Hearing Impairment,

- Infection in ear-Inflammatory
- Accidental
- Sensory-neural loss
- Genetic cause-chromosomal abnormalities
- Ear discharge

Locomotors Impairment,

- Arthritis
- Loss of limb

Deformity

- Accident
- Lack of immunization
- Vitamin deficiency
- Paralysis
- Encephalitis
- Deformity due to lunar eclipse
- Paralysis due to blood pressure, diabetics' rickets, beriberi etc.

Mental Retardation

- Malnutrition

Blood incompatibility

- Premature delivery
- Anoxia
- Head injury
- Frequent high fevers
- Traumatic birth injury or abnormal delivery

Estimates of the number of disabled vary a great deal depending on the definition; the source, the methodology, use of scientific instrument in identifying and measuring the degree of disability etc. It is estimated that the population of India is approximately 90 million out of these 12 million are blind , 28.5 million are with low vision ,12 million are hearing defects,6 million are orthopaedically handicapped, 24 million are mentally retarded, and 7.5 million are mentally ill .(Source-NSSO,1991)

A comprehensive country wide sample survey of persons with disabilities was undertaken by the NSSO in its 36th round, 1981 at the request of the ministry of welfare which indicated that 1.8% of the country's population had physical and sensory disabilities. There was no survey conducted on mentally retarded persons. It

was carried out by various research organizations that indicated that nearly 2-2.5%of the country's population suffered from mental retardation.

Another survey was conducted by the NSSO in 1991 to estimate the magnitude of the persons with disabilities in India indicated the following findings.

1. About 1.9% of the total population of the country that is about 16.15 million persons have physical or sensory disability which includes visual, speech, hearing and locomotors disability. Thus there was a slight increase in the disability over the decade in terms of absolute number and in terms of percentage.
2. In a separate survey of children (age0-14 years with delayed development ,it was found that 29% in the rural areas had developmental delays which are usually associated with MR.
3. The prevalence rate for physical disability was observed to be significantly more among males (22.77/1000) (16.94/1000)
4. As regard the state wise distribution of the physical disability, the state which have higher prevalence rate are Andhra Pradesh, Himachal Pradesh, Karnataka, Orissa, Punjab and Tamilnadu.
5. The rate of the physical disability in the urban (16.75/1000) areas was less as compared to the rural areas (19.75/1000).
6. About 12.3% of the disabled people identified were multiple handicapped.
7. Among physically disabled 25% of the disabled people in the rural area and the 20% in the urban areas are from such severe disabilities that they are not able to perform activities of self care and daily living even without aid.

The age-wise distribution per 1000 disabled has been derived by NSSO,1991 to be as follows:

Age group	**Visual**		**Hearing**		**Speech**		**Locomotors**	
	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban
0-4	04	05	N.A	N.A	47	47	27	30
5-14	24	21	85	80	262	261	224	223
15-59	255	304	387	377	539	513	487	503
60 & above	717	670	526	541	197	225	240	227

Note: source: report No 393 report on the disabled person 47th round July- December 1991.NSSO

Legislative actions in favour of PWDs

PWDs (equal opportunities and protection of rights and full participation) act1995

The act emphasizes on

- Prevention and promotional aspect of rehabilitation of PWDs like education. employment and vocational training, job reservation, research and manpower development of barrier free environment, rehabilitation, allowance, establishment of houses for PWDs etc .

- Grievance redressal mechanism in relation to the deprivation of rights of PWDs and implementation of related laws, rules, regulations, executive orders, guidelines etc.
- Being implemented with multi-sectorial collaborated approach and related ministries/departments of central government, state government and other appropriate authorities.
- Office of chief commissioner for PWDs shall:
    - Coordinate the work of commissioners
    - Monitors the utilization of funds disbursed by the central government
    - Takes step to safeguard rights and facilities made available to PWDs
    - Submits report to the central government on the implementation o f the act at such intervals as the government may prescribe.

Rehabilitation council of India act (RCI Act, 34 of 1992)

The rehabilitation of the disabled has been drawing the attention of the government of India since 1981(International year of the disabled). Lack of appropriate trained manpower has been one of the major constraints in the expansion of the rehabilitation services in the country. The training programmes in the country in the field of handicapped were isolated and adhoc in nature with no standard syllabi. There was no uniformity in the teaching curriculum run by the various institution at undergraduate, graduate and postgraduate level. It was therefore decided by the government of India in 1986 to set up a Rehabilitation Council of India, (RCI) who will be responsible for

1. Training policies and programmes to standardize the training courses for professionals dealing with PWDs.
2. To grant recognition to the institutions running these training courses.
3. To maintain a central rehabilitation register of the rehabilitation professionals.

The Government of India introduced a bill in the parliament to give statutory powers to the council for carrying out its duties effectively .The RCI Act 1992 of the parliament received the assent of the president of India on 1st September 1992 and the RCI Act 1992 came into force with effect from june1993.

RCI is presently regulating a number of training programmes nation wide at undergraduate, graduate, post graduate & other professional courses. The council has standardized 50 training programmes in different categories of disabilities i:e from certificate level to post graduate level and institutions recognized by the RCI conduct these programmes. The council keeps on updating & adding new training programmes as per the requirement of the country. More than 119 training institutions/universities have been accorded approval to run various training programmes in the field of special education/rehabilitation of the disabled. The council has also registered a large number of professional/personnel in the central rehabilitation register and issued them registration certificates. These certificates are valid for employment & self practice in their field of disabilities.

ROLE OF MINISTRY OF SOCIAL JUSTICE AND EMPOWERMENT

The Ministry of social Justice and Empowerment Government of India is running various schemes of assistance and concession for the welfare of the PWDs. The grants

are given by the ministry, subject to availability of funds to institutions recognized by the Rehabilitation Council of India to conduct specialized training programmes for the manpower development

NATIONAL TRUST ACT 1999

The National Trust Act 1999 provides for the constitution of a national body for the welfare of the people with autism, cerebral palsy, mental retardation, and multiple disabilities. The act mandates promotion of measures for the care and protection of the PWDs in the event of the death of their parents, procedure for appointment of guardians and trustees for the persons in need of such protection and support to registered organizations to provide need based service in times of crisis to the families of the disabled. Training programmes to care givers (grass root level workers) has been also introduced recently by National Trust for helping the anguished parents in need based rehabilitation service delivery at their respective houses.

SERVICE OF VARIOUS NATIONAL LEVEL INSTITUTES

There are a host of national level institutes which work to provide need based assistance to the disabled persons some of them are as follows:

- National institute for the mentally handicapped (NIMH)
- National institute for the visually handicapped (NIVH)
- National institute for rehabilitation training and research (NIRTAR)
- National institute for orthopaedically handicapped.

National handicapped finance and Development Corporation has the aim of assisting PWDs in following manner.

- to finance self employment ventures for the PWDs
- to extend loans for pursuing general professional technical education at graduate and high level for the PWDs
- to assist upgradation of technical and entrepreneurial skills for enabling beneficiaries to manage the production units efficiently

District disability Rehabilitation Centres (DRC) encapsulates following rehabilitation service packages.

- Facilitation and provision of disability certificates
- Assessment on the need of assistive devices
- Provision/fitment/follow-up / repair of assistive device
- To provide comprehensive rehabilitation services to the rural disabled through a camp approach in the villages.
- To provide services for prevention ,early detection, medical interventions, surgical correction, fitment of artificial aids and appliances ,physiotherapy, occupational speech therapy, vocational therapy, job placement in local industries and rural settings

VARIOUS OTHER PROVISIONS FOR THE PERSON WITH DISABLILITY

The problems of disabilities are vast and its impact on the People with disabilities is among the poorest of the poor in the community. Children with disabilities are especially oppressed and are unable to voice their concerns.

IEDC scheme (Integrated Education of Disabled Child):

The education of these children has historically followed the charity /segregation /special schools/integration approach. This IEDC is a scheme for the education of the disabled children. The Govt. in its IEDC scheme (Integrated Education of Disabled Child) employs Resource Teachers to teach the children with disabilities to additional curricular concepts of Braille, Orientation and Mobility, Auditory and speech training etc. Due to the inability of the general teacher to impart learning to the children with disabilities, the resource teacher also had to teach the general curricular concepts to these children. This led to physical integration and the children were referred to as Special children or children belonging to the Resource teacher. This led to further segregation. The other problem experienced was that just as the general teacher was not equipped to teach the children with disabilities the resource teacher was also ill equipped to teach the children with disabilities the general concepts of the curriculum as he/she was trained in special education concepts only.

Education:

India has a significant proportion of Children with disabilities in & around but less than one per cent have access to education. There is an urgent need to ensure the provision of education for disabled people. Research on designing and developing new supportive devices, teaching materials is being done to give a child with disability equal opportunities in education. Several factors like necessary changes in staff training for educators, parental support, community involvement, and inter-agency co-operation are being emphasized. The policy *Inclusive Education* represents a supportive approach to serving those with special needs. In an ideal system of Inclusive Education, the general education itself should make the education of disabled children as its integral part. This implies that the general class room teachers should be equipped with skills to address the educational needs of children with disabilities with minimum or no assistance of specialist resource teachers. This calls for strengthening the pre-service general teacher preparation programme with the inclusion of adequate component of the education of disabled children in the curriculum. Therefore Inclusive Education means, creating effective classrooms where educational needs of all children addressed irrespective of ability or disability. Most people feel that educating a child with disability in general school is inclusion but it can be treated as total inclusion only when the general classroom teachers take most of the responsibilities for the education of all these children.

The Sarva Shiksha Abhiyan (SSA):

The SSA is being implemented by the Govt. of India through the education departments of various States. One of the provisions of the Sarva Shiksha Abhiyan (SSA) is the identification of children with disabilities who are of school going age both within and outside the educational system.

ICDS (Integrated Child Development Services):

The Integrated Child Development Service is perhaps the most comprehensive programme for the child welfare in the country. It is meant for the children in the age

group of 0-6 years and the nursing and the expecting mothers. It takes a holistic approach of the child and attempts to improve both the pre natal and the post natal environment. Under this scheme a package of services consisting of supplementary nutrition immunization and health check ups, referral services, nutrition and health education, growth monitoring and non formal education is provided. The ICDS Supervisors and Anganwadi workers who will be appointed will also be trained to identify and rehabilitate children with disabilities. The constant monitoring over a period of time will ensure that the children receive appropriate services. The Portage kit will be distributed to all the Anganwadis in the State. Duplication of this training program in other states would mean that all children in the age group of 0-6 years would receive intervention for their holistic development. Efforts are on to persuade other states to undertake a similar training program for their grassroots workers. Preparation of all children to enter mainstream education would not only increase the quality of life for these children but would also ensure that the drop out rate is lowered and the learning achievement of children is enhanced. Since the drop out rate would reduce, children getting into labor or begging would also be reduced.

POVERTY ALLEVIATION SCHEMES

The section 40 of the PWD act 1995 provides 3% reservation in all poverty alleviation schemes for the benefits of the person with disabilities. Accordingly under all the poverty alleviation programmes the above safeguard has been provided

JGSY SCHEME:

Under the JGSY scheme, 3% of the annual allocation is earmarked for construction of houses for BPL, physical and mentally challenged people

SGSY SCHEME:

Under the SGSY schemes 3% of the swarojgari (Self Employed) is assisted should be from the category of PWDs .The amendments in the guidelines in order to suit the needs of disabled people which are under consideration

- Up to 20% of the members in a SHG of disabled persons may be from non disabled BPL families.
- Subsidy for individual swarojgari would be on par with the ST/SCs that is 50% for the project cost with a maximum of Rs.10,000/
- Disabled persons from above poverty lines would be eligible for subsidies under SGSY, even when a member of the family has been assisted under the SGSY/ a disabled from the same family could be considered for assistance under the scheme.

Measures taken by Govt. of Orissa for Promoting education and Rehabilitation of Disabled-Leading to Zero Rejection:

The Women and Child Development Department looks after the training, care and education of disabled.

1. Free and Appropriate Education
    - Grant in aid to 50 special schools in the state run by NGOs : 18 for visually impaired, 21 for hearing impaired, 11 for mentally retarded
    - 2939 disabled children of different categories are enrolled in these schools.

- Apart from this, 19 special schools are running in the state with Govt. of India assistance
- NGOs are encouraged to set up new special schools in the districts where there is no such facility.
- Braille press has been installed at the Red Cross School for the Blind, Berhampur with state assistance.
- Orissa Association of Blind is also involved in a Braille transcription Project with state assistance.
- Free books, study materials, uniforms, escort allowances are provided to disabled students under IED component in selected districts of DPEP by MHRD.
- All districts will now be covered under Sarva Sikha Ahbijan (SSA)
- NIMH sponsored centre for Training of teachers, NIVA sponsored centre for training of teachers of Visually Handicapped; NIHH sponsored centre for training of teachers of Hearing impaired are operating in the state. Approximately 60 to 70 teachers come out of these centre.
- Scholarships and stipends are being provided to disabled students studying in normal schools / colleges/ vocational training institutes. 3652 disabled students received such benefits up to 2002.
- Special education is now being provided to CP children with grant in aid form the state to such institution.

2. Aids and Appliances
    - ADIP scheme is being implemented through registered NGOs, Indian Red Cross, DRC, Alimco, & NIRTAR with financial assistance from GOI. Disabled persons with an income of 5999/- p.m. are provided aids and appliances which costs between 50/- to 6000/- free of cost. The income gross above 5000/- has to pay 50 per cent cost.
    - Special aids and appliances like crutches, sticks for blind, tricycles, hearing aids are given free under state assistance.
3. The State Govt. Has appointed the Secretary-cum-Commissioner to Govt. in Women and Child Development Department to monitor and supervise implementation of PWD Act. 1995.

Economic Rehabilitation

- 4 Vocational Training Centers are running in the State with State support .
- NHFDC is providing loans to disabled persons through Mahila Vikas Samabaya Nigam.

Transport Subsidies

- Govt. has allowed 100% concession facilities to blind and orthopedically handicapped persons with up to 50% disability and above along with an escort who gets a 50% concession.

- The orthopedically handicapped persons with 40% disability and above but below 50% are allowed 50% concession without an escort.
- Mentally challenged persons are allowed 100% concession along with an escort at 50% concession.

Infrastructure

- Regional Rehabilitation Centre for Persons with spinal injuries and other orthopedic disabilities has been set up in SCB Medical College, Cuttack.
- VRC is functioning at Bhubaneswar for Physically handicapped
- ALIMCO is functioning at Bhubaneswar.

National Programme for Rehabilitation of Persons with Disabilities (NPRPD) is being implemented by state govt. through Gram Panchayat to State level agencies.

- Steps are being taken to train selected MRWs, CBR, and Master Trainers through RCI/ RRTC in regional language.
- There is a state level Institute of Disability rehabilitation centre at Bhubaneswar working under NPRPD scheme.
- DDRCs- Five DDRCs are functioning in the districts of Koraput, Phulbani, Kalahandi, Mayurbhanj, Sambalpur

National Trust

- Local level committees have been set up in all 30 districts in keeping with the Act.

Disability Certificate

- Two days in a week have been fixed for issue of disability certificate by Medical Boards set up for the purpose in the entire district.
- Campaigns, seminars are being conducted to build awareness about disability and various programmes.

All these measures directly and indirectly influence the enrolment of disabled children into an appropriate system of education and service thereby contributing to no rejection.

ROLE OF HEALTH DEPARTMENT IN PREVENTION & TREATMENT OF DISABILITY

Department of Health & Family Welfare has been working on the immunization of children & mother which is an inevitable step of preventing the child from Polio & other infections which directly or indirectly leads to disability. In addition to promote better prenatal & antenatal care the expectant mothers are distributed with vitamin & iron pills during the course of pregnancy. Mothers are constantly educated about appropriate intake of nutritious food available within their reach for combating the birth of any malformed baby. Intake of the medicines & regular health check up of mothers are monitored by the Multipurpose Health Workers.

In every district a District Medical Board constituting Orthopaedician, Opthalmologist, ENT specialist, Audiologist & psychiatrist headed by the Chief District Medical Officer is entrusted with the certification of PWDs on weekly basis.

Recently policy has been formulated to orient all medical officers working in Primary Health Centres on disability management. Hence under the national programme on "Three days Orientation of PHC medical officers on disability management" had been organised by the recognized institutions of RCI in different states. It has been found that through this collaboration of RCI with the ministry of health has enabled the medical officers for counseling of parents about the exact condition of the children & the referral of cases with disabilities to appropriate rehabilitation centers. Many more other training programmes are on the process of anvil for the doctors to give them more insights on disability issues.

REVIEW OF LITERATURE

The UNICEF has emphasized the following facts about the children with disabilities. The severe disabilities of the million of children could have been prevented. Children with physical, mental and sensory impairment are very often denied the fundamental care and stimulation the all children need for their growth and development. The disruption of the ordinary process of child development can produce a more serious handicap for the disabled child than the impairment alone would have caused. The main causes of impairment and disabilities inadequate nutrition, difficulties at the birth, preventable diseases, infections and accidents are far more likely to affect people who are poor and who have the least access to human services. The birth of an impaired child or the occurrence of the disability can place additional burden on the whole family. It can reduce the capacity of the family foe the economic survival and may keep it locked in a cycle of poverty Only occasionally do the programmes for improving the lives of children and their families in health, nutition, basic education, family planning and social welfare fulfill their vital role in preventing and reducing disability. Generally there is ignorance about the fundamental cause of disability, its prevention and possibilities for rehabilitation .Families and communities through out the world as a result, needlessly are making their children disabled and handicapped.

In a study conducted by the Orissa based voluntary organization, NYSASDRI in 2004 among 103 PWDs is found that majority of the studied subjects or their family members lack awareness of the availability of rehabilitation centers in their vicinity. Finding the delayed developmental mile stones of the children they end up running to the local physicians, who only suggested for the intake of vitamins & appropriate diet for the accelerated growth of the child. PWDs either they don't know about the issue of disability certificates by District Medical Board or the small fraction of sample who know or have received it have shown distrust on Govt proactive policy of this certification, as they don't find any benefits out of this disability certificates.

A project entitled "Circle of support for People With Disabilities & Autism in India & EU- Developing qualification modules for person centered community inclusion networks with vulnerable individuals" has been implemented by EU-India Economic Cross Cultural Programme of the European Union in three countries of Germany, U.K & India for the identification of existing support circles around the PWDs & Autism . Outcome of this identification in the three countries will lead to the development of course modules in universities which will create students/professionals for facilitating the informal networks in the community. This two year programme has been

implemented in the above three countries since year 2004 simultaneously has the cross cultural scenario is being shared by partner implementers time to time.

Paper presented by Jayalakshmi (2004) in the National Conference on children with disabilities reveals success stories of integrating children with Autism in normal schools with an extra attention of teachers & administration of a specific curriculum.

Farida Raj & Vidyavathi (2004) basing on their studies on 317 school going children have recommended for a proper assessment, early detection and management of the vision related problems in children to overcome their learning difficulty.

Plumber et al (2004) under the APAWMR project had implemented an intervention programme for the infants (0-3 years age group) at high risk for becoming mentally retarded in the state Andhra Pradesh and found rewarding experiences of infant survival with normal development & sustained improvement on repeat assessment.

A PIED evaluation study was undertaken by Mani (1993) indicated that enrolment of disabled children has increased, including severely disabled, boys being more than girls. The disabled children perform well except for mentally retarded children who were inferior to the non disabled children.The retention rate is higher (about 95%) as special teachers are committed. Orissa has no full time IED teachers for all schools. Teachers, parents, community members are more supportive of IED. Peer group relation with non disabled children is also acceptable. There is need for more TLM. Composite area of approach for IED is more effective than arbitrary school approach. There is a need for General teacher preparation, restructuring manpower in PIED, redeployment of teachers to special education, strengthening the multi-category training programme, avoidance of mislabeling etc.

OBJECTIVES OF STUDY

The study which was conducted in the Gondia block of the Dhenkanal district had the following objectives:

- To identify the locally existing support services for the disabled children.
- To understand the role of a family, friends and relative and different institutes providing support to the CWDs.
- To find out the causal factors leading to disability among children in the studied area.

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Chapter-2

Area Profile of the Project Area

The state of Orissa occupies the 10th position in the country both in territory and population. The capital of the state is Bhubaneswar. Total population of the state is 36804660, including 31287422 rural inhabitants and 5517238 urban inhabitants (according to the census conducted by the government of India, 2001).The state is a land of forests and the population-Tribals and the Scheduled Castes account for nearly 40% of the population of the state .The state has suffered nature's wrath and adversity which is evident from the natural calamities like flood, cyclones, drought and famines. The study was conducted in 28 villages of the Gondia block which are shown in the table below:

Sl No.	**Name of the village**	**Name of the gram Panchayat**
1	Anandapur	Mathatentulia
2.	Bega	Bega
3.	Bhaliapata	Kashipur
4.	Bellamalia	Pingua
5.	b.karagola	Digambarpur
6.	Chadakmara	Nihalaprasad
7.	Digambarpur	Digambarpur
8.	Jambu	Mathatentulia
9	Jharada	Sadangi
10.	Kashipur kokrajhar	Kashipur
11.	Kashipur	Kashipur
12.	Kallana	Mathatentulia
13.	Laulai	Laulai
14.	Lahada	Kashipur
15.	Mathatentulia	Mathatentulia
16.	Nityanandpur	Nihalaprasad
17	Nilkanthapur	Mathatentulia
18.	Nuaichhapur	Khandabandha
19.	Nuarucha	Mathatentulia
20	Santhasara	Santhapura
21	Sadangi	Sadangi
22	Srimantapur	Bega
23	Sologasdia	Ratanpur
24.	Phuljhar	Khonkira
25.	Palagandua	Sadangi
26.	Purshottampur	Mandar
27.	Chottatentulia	Khonkira
28	Purana kashipur	Kashipur

LOCATION AND TOPOGRAPHY:

Dhenkanal district is situated in the north east of Orissa. The district is bordered by Keonjhar in the north, Cuttack in the south, Jajpur in the east, and Angul in the west. The district is full of mountains and is divided into northern and southern halves by the mighty Brahmini River. The Gondia block, where the study was carried out is on the extreme east of the Dhenkanal district. The block spreads over an area of 397.35 square kilometers and the majority of the land is occupied by forests .The area is a plain area and is circled by massive mountain ranges .The 28 villages where the study was conducted are located at the foothills of the sal-covered mountains. The block head quarter is situated at the distance of 30 kilometers from the district Dhenkanal while the villages are situated at a varied distance of 30-90 Kms range.

The PWD road which connects places like the Dhenkanal, Gondia block and Mandar village is the biggest concrete road which one has to travel through while going to these villages. The other concrete road which connects the villages is the Barapada road but this is a relatively smaller road. When moving in the Barapada road the Kashipur centre of NYSASDRI comes on the way, which was the field centre for the researchers. This centre is approximately 14 Kms from the Santhasara office of the organization and the project villages are located at an average distance of 5 to 30 Kms from the field centre of NYSASDRI, the base centre of field investigation. The Barapada Community Health Centre (CHC) is the most accessible CHC for most of the villages at the same time there are PHCs present at Khankira, Pingua, Joranda, Karamul and Deogaon . In addition to this a total of 22 sub centres at Panchayats of Gondia Block which is operated by a multipurpose health worker.

The government of India has decentralized the power and developed a system called swayat sasan . According to this, the local self government is a three tier administrative system where at the bottom level Gram Panchayat resort, at the middle there is the Panchayat Samiti and at the top i:e the district level there is the Zila Parishad . The head of the village is the Sarpanch.

DEMOGRAPHIC SET UP

As per the census conducted by the government of India in the year 2001, the total population, rural and urban population by sex in the Gondia block is as follows

	Total Population		**Rural**		**Urban**	
	Male	**Female**	**Male**	**Female**	**Male**	**Female**
	70,110	67,374	70,110	6,78,374	000	000
Total	**1,37,484**		**1,37,484**		**000**	

The region is primarily inhabited by schedule castes and schedule tribes .The STs Account for 30% SCs for 23% OBC's for 27% and the rest 20% account for the GC's of the total population of the block. The ST population comprises of the Mundas ,Sowras, Santhals,Khairas, Sitras, Kolhas etc,.The SC's comprise of Panos, Khaibatras,Dhobas, Chamars, and Hadis, the OBC's are the Banyas,Badhais,Kamaras. Teli, Gudia, Gaudas, and Vyabasais the GC's which are the least in number consist of the Brahmins, Kshatriyas, Karana, and Paika.

Demographic Profile of Gondia

Indicators	*Number*
Total household	30116
Total population	143263
Total male population	70149
Total female population	23293(16.3 %)
Total ST population	27049(18.9%)
Total illiteracy	46.7%
Total female illiteracy	57.3%
Total no of villages	196
Total no of G.P	27
No of CHC	1
NO OF PHC	6
No of Primary school	124
No of M.E school	48
No of Secondary school	25
Source- Census of India 2001 & District Statistical Hand Book 1999	

THE SOCIO ECONOMIC CONDITION

Gondia block is the most backward block of Dhenkanal district of Orissa and the residents of the block are most neglected and lead a pathetic life when compared to the other backward district of the state. The poverty in the villages is manifested in the poor education, unemployment, malnutrition, low health status, and unhygienic conditions in the village.

OCCUPATION

The major occupation of the inhabitants of the Gondia block is agriculture, daily wage earning and collection of forest produces. The other occupation of the people is pottery, carpentry, business, etc and very few are service holders. On an average 80% of the population earn their livelihood through agriculture and daily wage earning. The ST/SCS and the OBCs are the ones whose economic status is very low and they are the ones who completely depend on daily earning and collection of forest products. More than 60% are small and marginal farmers or landless farmers who go for single crop cultivation that is paddy. A large number of village houses is of semi pucca type and very few houses are of concrete type.

HEALTH STATUS

The general health status of the villages is very low and most of the villagers specially the children are preys of malnutrition. The major type of diseases which are prevalent in the villages are water –borne diseases, vitamin deficiency diseases, malaria, TB, skin diseases, eye infection, night blindness etc. The present scenario of the disability prevailing in the block, discussed in chapter 4 of the volume and the high incidence rate of anemia among women are evidences of the low health status of the inhabitants.

LITERACY LEVEL

The literacy rate of the block is 48% .The villages are facilitated with education centers and there is at least one primary level school under the Sarva Siksha Abhiyaan. In spite of these, the level of literacy in the villages is very low and the dropout rate is also high. The low economic status and lack of awareness are probable causes of low literacy level in the region.

RELIGION

The main religion in the region is Hinduism and there is hardly any Muslim or Christian family. There are cultural difference between the tribal and the other caste. The tribal are the worshippers of nature. "vandevta" is their presiding deity. The tribal community celebrates Dashahara, Pousa Purnima, Makar Parba, Pana Sankrati etc. The other caste excluding Brahmins have their own tradition. The Brahmin worship 13 festivals mainly in twelve months including Raja, Srigundicha, Gahmapurnima, Chitalagi Amabasya, Ganesh Puja, Saraswati Puja, Kartika Purnima, Kumar Purnima, Prathamastami, Manabasa Gurubar, Dolapurnima, Holi and so on. In case of OBC, these festivals are rarely observed. But the milkman observes Dola Purnima with much pump and luxury. A strong bar in this area prevails on un-touch ability. The SC and ST people are not touchable by the OBC and Brahmins. The parents or relatives of SC and General Caste bride/bride groom arrange the marriage for their wards, while love marriage is widespread among the tribal. Among general caste people, inter caste or love marriage is seen with every amount of suspicion and bad remarks.

FOOD HABIT

The staple food habits of general caste community are mostly vegetarian with the varieties of rice, dal, and vegetable curry & seldom with non-vegetarian dishes. The tribal generally takes more non-veg. Hadi community consumes beef, which is avoided by other communities.

Village profile of some selected villages is as follows:

1. ***Name of the village: Mathatentulia***

   Total population: 1475
   No. of male: 757
   No. of female: 718
   Total sc population: 369
   Total sc male: 196
   Total sc female: 173
   Total ST Population: 437
   Total ST Male: 227
   Total ST Female: 210

   Total no. of wards: 5
   Literacy rate: Not Available
   No. of literate SC: 368
   No. of literate ST: 387
   No. of literate others: 442

Illiterate
No. of SC: 55
No. of ST: 28
No. of other: 92

Total no. of handicapped-12
SC: 3
ST: 4
Others5
Total no. of hamlets-1

Nearest:
Post office: Mathatentulia
ICDs: Mathatentulia
Police station- Gondia
Bank: Sadangi
Disability camp conducted: Mathatentulia
No. of tanks-3
No. of canal: 1
No. of tubewells: 7
Primary school: 1
Middle school: 1
High school: 1

Nearest college: Sadangi
Nearest blind school: Dhenkanal
Nearest range office: Sadangi
Nearest revenue office: Sadangi
Nearest bus stand: Baripada

Main occupation:
Farmers-50%
Service: 5%
Daily labour: 45%

No. of children according to age group
0-6 months-19
6-months-1year-44
1-3year-93
3-6year-176
No. of shgs-12
Livestock center-: Mathatentulia

2. ***Name of the village- Digambarpur***

Total population-1083
No. of male-526
No. of female-557
Total sc population--646
Total sc male: 318
Total sc female: 328
Total general population: 437
Total general male: 208
Total general female229
Total no. of wards-5
Literacy rate: Not Available
No. of literate population: 822
No. of illiterate population: 261

Total no. of handicapped 12
SC: 9
ST: Not Available
Others: 3

Nearest:
Post office
ICDs: Digambarpur
Police station: Gondia
Bank:Sadangi
Disability camp conducted: sadangi
No. of tanks: 2

No. of canal: 1
No. of tubewells: 7
Primary school: Digambarpur
High school: Nuagarh (2kms)
Nearest college: Sadangi (7kms)
Nearest blind school: Dhenkanal
Nearest range Office: Pingua (6km)
Nearest revenue office: Sadangi
Nearest bus stand: Digambarpur

Main occupation
Farmers: 10%

Service: 10%
Daily labour: 80%

No. of children according to age group
0-6 months: 9
6-months-1year: 8
1-3year: 37
3-6year: 45
No. of SHGs: 15

3. ***<u>Name of the village: Sadangi</u>***
Total population: 4846
No. of male: 2453
No. of female: 2393
Total sc population: 519
Total sc male: 243
Total sc female: 276
Total ST Population: 782
Total ST Male: 405
Total ST female: 377
Total no. of wards: 7
Literacy rate: Not Available
No. of literate SC: Not Available
No. of literate ST: Not Available
No. of literate others: Not Available
Illiterate: Not Available
No. of sc: Not Available
No. of ST: Not Available
No. of others: Not Available
Total no. of handicapped: 15
SC: 4
ST: 3:
Others: 8
Total no. of hamlets: Not Available
Nearest:
Post office: Sadangi
ICDs: 3 in Sadangi
Police station: Gondia
Bank: Sadangi
Disability camp conducted: Sadangi
No. of tanks: 3

No. of canal
No. of tubewells: 14
Primary school: 1 in Sadangi
High school: 1 in Sadangi
Nearest college: Sadangi
Nearest blind school: Dhenkanal
Nearest range office: Sadangi
Nearest revenue office: Sadangi
Nearest bus stand: Sadangi

Main occupation
Farmers: 25%
Service: 10%
Daily labour: 65%r
no. of SHGs- Not Available

4. ***Name of the village: Chotatentulia***

Total population: 849
No. of male: 426
No. of female: 423
Total others population: 444
Total others male: 215
Total others female: 229
Total ST Population: 388
Total ST male: 211
Total ST female: 177
Total no. of wards: 2
Literacy rate: Not Available
TotalNo.of literate: 353
Illiterate::496
Total no. of handicapped: 4
Sc: Not Available
ST: 3
Others: 1
Total no. of hamlets: Not Available

Nearest:
Post office: chota tentulia
Police station: Gondia
Bank: Pingua
Disability camp conducted; Pingua

No. of tanks
No. of canal
No. of tubewells: 2
Primary school: Chotatentulia
High school: Konkira
Nearest college: Pingua
Nearest blind school: Dhenkanal
Nearest range office: Pingua

Main occupation
Farmers-20%
Service-5%
Daily labour-75%
No. of children according to age group
0-6 months-8
6-months-1year-22
1-3year-28
3-6year-61
no. of SHGs-livestock center- in Sadangi

5. ***<u>Name of the village: Sologadia</u>***

Total population: 1535
No. of male: 806
No. of female: 729
Total sc population: 142
Total sc male: 81
Total sc female: 61
Total ST Population: 279
Total ST: male: 140
Total ST Femalie: 139
Total no. of wards: 7
Literacy rate
No. of literate sc: 34
No. of literate ST: 124
No. of literate others: 457
Illiterate: 859
No. of sc: 108
No. of st: 155
No. of others::596
Total no. of handicapped: 12
Sc: 2:

ST: 3
Others: 5
Total no. of hamlets
Nearest:
Post office: Ratanpur
ICDs: Ratanpur
Police station: Not Available
Bank: Not Available
Disability camp conducted: Pingua
No. of tanks: 3
No. of tubewells: 1
Primary school: Sologadia
High school: Ratanpur
Nearest blind school: Dhenkanal
Nearest range office: Pingua
Nearest revenue office: Not Available
Nearest bus stand: Not Available

Main occupation
Farmers-10%
Service-5%
Daily labour-85%
No. of children according to age group
0-6 months-19
6-months-1year-26
1-3year-59
3-6year-149
No. of shgs-7
Livestock center

During the fieldwork the investigators had the privilege to work with a state level NGO NYSASDRI. A brief profile of the organization is given below:

ORGANIZATION PROFILE

National Youth Service Action and Social Development Research Institute (NYSASDRI) have been actively working since more than two decades on developmental issues in Orissa. It is one of the leading non-government –organization (NGO) committed to the upliftment of the communities in Orissa .The organization was founded in the year 1973 as a village youth club named, Bapuji Absara Binodan Kendra in the village of Santhasara in Gondia block of Dhenkanal district, Orissa. In the beginning the club was limited within the village Santhasara through recreational activities only. In the year 1982,the club was renamed as NYSASDRI and started its endeavor for development of rural poor –the marginalized and the weaker sections of the society since then the organization has constantly been involved in various activities related to health, education, environment, sanitation, agriculture, food security, livelihood support, research, and advocacy etc.

AREA OF OPERATION OF THE ORGANISATION:

LEGAL STATUS:

NYSASDRI is a registered voluntary organization under the Indian societies registration act XXI of 1860. The organization is also eligible to receive and spend foreign contribution under the foreign contribution regulation act (FCRA) under the ministry of home affairs (GOI). It is also registered under income tax act 1961 and permitted to accept donation under section 12(A) and 80(G) of the act.

BRANCH OFFICES:

1. Kalihata Keonjhar
2. Majhikanda, jagatsinghpu
3. Chigudipal, Sukinda, Jajpur
4. S.tandapilli, Malkangiri
5. Hukumtola, Rayagada

MAJOR ACTIVITIES OF NYSASDRI DURING THE COURSE OF ITS JOURNEY

- ***SUSTAINABLE SOCIO-ECONOMIC DEVELOPMENT OF TRIBAL COMMUNITIES:***

  The project on sustainable socio economic development of tribal communities is running in 34 villages of Telkoi block in Keonjhar district. This has changed the life of tribal women in the project area in an effective manner by providing them with social and economic empowerment.

- ***COMMUNITY ORGANIZATION AND WOMEN GROUPS:***

  NYSASDRI has successfully motivated the village communities to maintain a record of their development and to discuss , issues such as community saving schemes ,forest protection, recovery of loans ,management of groups, and to sort out problems related to drinking water on a regular basis with its capacity building ,training camps, NYSASDRI is successfully imparting training to groups at villages, gram Panchayats and the central levels on leadership, roles, group responsibilities and achievement motivation.

- ***EDUCATION OF TRIBAL CHILDREN:***

  Child development centers are running in 16 villages where 450 children have been educated at the primary level .The community has taken over the responsibility to manage the centers and are encouraging children for education.

- ***RELIEF AND REHABILITATION:***

  NYSASDRI drug rehabilitation centre in Santhasara had provided diagnosis and health check up facilities and counseling to drug addicts under treatment.

- Need based services were provided to leprosy cured patients through vocational training, placement services, awareness counseling and health services.

- Basic feeding ,accommodation, medical care, legal support, and relaxing at homely atmosphere has been provided by the short stay home programme for the distressed women .These women have encountered problems that relate to family separation unmarried motherhood, sexual harass ness, mental retardation and widowhood.

- Social counseling ,orientation on daily living ,facilities such as bus passes, pension, aids and appliances and economic support for rehabilitation have been provided by NYSASDRI to the rural disabled with speech ,hearing and locomotion disabilities, learning difficulties, and mental retardation

- Bonded child laborers in the age group of 6-14 years have been freed and provided with education, health, and income generating activities.

- ***Through its AAG (ADOPT A GRANNY) scheme:***

  NYSASDRI has successfully been providing elders who are not getting support from their family or relatives, with essential commodities such as food stuff, oil, mosquito net, tea and sugar, mats, umbrellas, pocket money, etc.

- After the super cyclone that devastated much of Orissa in 1999 NYSASDRI prioritizing the needs of communities provided assistance to the people of 56 villages from 4 blocks construction of kanga houses. These were locally acceptable ,cost-effective, durable, wind resistant and easily repairable. Relief materials were also supplied to the affected families, containing rice, dal, mustard oil, mat, umbrellas, clothes, polythene sheets, etc.

- ***HEALTH CARE FOR WOMEN AND CHILDREN:***

  Through regular health check up and educational camps, children and pregnant mothers are provided with health services that help them to cure minor contagious diseases and other ailments.

- ***INCOME GENERATION:***

  NYSASDRI has carried out a number of income generation trades that include milch-cow, goat, sheep, and bullock rearing, rice business, bamboo work, petty shop, trolley rickshaw, kitchen gardening and tailoring, all of which have helped the beneficiaries lead a good quality of life. These programmes were also implemented in the after math of the super cyclone

- ***HEALTH AND HYGIENE:***

Dissemination of information on hygienic living practices, promoting the practice of visiting primary health centers and to make use of medical facilities, cataract operations, dialogues with the mining authorities for reduction of pollution in certain areas, health, health check up camps, immunization camps, sterilization camps, safe drinking water awareness camps including open well chlorination, pulse polio and literacy for women and children have all been undertaken by NYSASDRI.

- NYSASDRI's mobile medical unit is running in Sukinda block of Jajpur district. It includes well-experienced medical staff catering health services to the tribal population providing health cards to the patients for their treatment.

- ***SEX AND REPRODUCTIVE HEALTH EDUCATION :***

  NYSASDRI conducted a massive campaign and a no. of work shops and seminars and sex education and reproductive health rights that helped to raise awareness about the key stakeholders in the community to include sex education in school curriculum of Orissa.

- ***NON FORMAL EDUCATION A STEP TOWARDS PRIMARY EDUCATION:***

  In places where there were fewer educational facilities and the people were less inclined to send their children to formal schools NYSASDRI has non formal education centers. These centers enabled the children of that area to join the formal system of education at primary level.

- ***EYE HOSPITAL RESTORING EYE SIGHTS OF THE ELDERS AND CHILDREN:***

  In the absence of eye care and treatment facilities for the elders in remote areas who suffer from eye problems like cataracts and other eye related diseases, NYSASDRI is conducting eye camps at different villages for cataract operations and is spreading awareness amongst people regarding eye care and prevention of eye related diseases .since October 2003 a well equipped hospital named as Kalinga eye hospital and research centre has been established in the heart of Dhenkanal town.

- ***SAFE DRINKING WATER IN THE TRIBAL AREAS:***

  In the tribal areas the facilities for safe drinking water are in adequate. The people have no alternative but to use water from ponds streams, and unhygienic wells. This is a potential health risk. In order to ensure the supply of safe drinking water to the tribal NYSASDRI has provided the facilities of tube wells, sanitary wells and open wells.

- ***ENVIRONMENTAL CONCERN:***

  NYSASDRI, under its environment protection plan has completed planting in hundred acres of land along with specialized herbal plantation in hundred seven villages. It has set up a joint forest management committee with forty seven members to ensure forest reservation in addition to this 45 environmental awareness camps (pad yatra) have been arranged in 38 villages.

- ***INFRASTRUCTURE DEVELOPMENT :***

Under its infrastructural development plan NYSASDRI has been able to provide check dams, sanitary wells, bridges, roads, hand pumps, and bore wells to improve the living standard of the people.

As a state level voluntary organization, NYSASDRI aims to reach out to the unreached and every under privileged person in Orissa. NYSASDRI believes in the continuing struggle of the impoverished section of the society by attempting to tackle the underlying problems at grass root level. NYSASDRI faces challenges with strong dedication and hard working attitude in order to achieve its goal.

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CHAPTER- 3

Methodology

The present volume on the topic "Existing circle of support for the disabled children & autistic in rural areas'' has been compiled after extensive survey in order to collect data for the same. As per the topic the data has been collected from the rural areas of Orissa .The survey had been conducted on the children with varied disabilities and their friends, families, relatives and neighbors in the rural areas.

DURATION:

The entire field work & report preparation has been done within a duration of 45 days from 10th may 2005 to 25th of June 2005 in the 28 villages of Gondia block in Dhenkanal district in Orissa. In fact the investigators were under the summer placement programme of Xavier Institute of Social Science, Ranchi, Jharkhand. The project work has to be utilized by them for the partial fulfillment of P.G Degree of Rural Development course.

SAMPLING:

The subjects of study were child with disabilities (CWDs) who fall in the age group of 0-14 years of age. The study aimed at covering a spectrum of disability occurring in the children of this age group and to know the various kind of support a child with disability received. These support could be financial,social, emotional & psychological. The study also aimed at knowing the socio economic status of these families. Furthermore the sampling was purposive so the pre listed villages had been chosen for the research work.

For the research work the family, relatives, and friends in order of preference had been chosen as the target group or samples. The sample size for the study is 60.In order to cover a wide range of disability occurring in the children of different age (0-14years) also in of different castes and villages. The kind of sampling done was purposive random sampling where the units were selected from the universe for the research.

METHODS OF DATA COLLECTION:

The method of assessment is of both qualitative as well as quantitative. The methods of data collection are of the following type:

- ✦ Semi structured interview
- ✦ Non-participatory observation
- ✦ Interview schedule/questionnaire
- ✦ Case study
- ✦ Focussed group discussion

Various PRA tools:

- ✦ Social mapping
- ✦ Chapatti diagram
- ✦ Matrix ranking
- ✦ Time analysis

1. OBSERVATION

Observation is a systematic study through the senses of occurrences at the time they occur. It is a proper method in empirical science. Everything in science is obtained through observation. The social investigator can not conduct any research without observation. He is in the field of observation. The observations are broadly of two types.

Participative

Non –participative

During this study the non participative observation has been an important tool for the data collection, especially for the collection of the qualitative data .Much of the observation was done while communicating with the disabled children, their families, friends, relatives. Observation has not only made it simple for the researcher, but has also helped him for the generalizations of the trends. It has also helped in getting greater accuracy by providing necessary insights on the research for giving a meaning full interpretation of the factual data presented in the statistical form. The first hand information has been very important for knowing the attitude of the disable child towards the society, the attitude of the society toward the disabled children and most importantly the attitude of the parents towards their disabled child.

2. SEMI STRUCTURED INTERVIEWS:

The semi structured interviews have been another important tool for gathering first hand qualitative and quantitative information for the study. During the semi structured interview the investigators served as the facilitator and directed the discussion or the conversation in a particular direction by asking few key questions and the rest of the information was given by the interviewee. The key question in this study was “what were the main problems faced by the disabled children? “This question has been very helpful in knowing the attitude of the disabled, the attitude of the society, attitude of the parents of the CWDs etc. Such questions had led the target group to answer about the various aspects of the disabled child like the medical, financial, social, emotional educational and other such aspects.

3. INTERVIEW:

A researcher need not rely completely on the senses for the purpose of observation and data collection .An interview is a conversation between the respondent and the researcher. It can be done simultaneously and the required information can be jotted down in the interview schedule. The interview schedule caters to both the open ended and the closed ended questions. Information concerning the pre natal, post natal care, the immunization, diseases which has been occurring in the history of the child, the family type etc. has been fetched from the interview schedule.

4. CASE STUDY

Case study is a holistic study about the unit of research. It is an intensive study and historical examination. It gives qualitative information about the subjects of the research.

The case study is generally narrative and descriptive. The case Studies of the disabled children have been an imperative tool in knowing a great deal of information about the social, economical, emotional psychological aspects of the disabled children. It has been very helpful in the generalization of the trends.

5. FOCUSSED GROUP DISSCUSSIONS:

The focused group discussion is a kind of discussion where the small group of the target respondents is left to discuss on a given topic. The researcher sits aside and notes down the relevant information concerning the study. The FGD in this study has been conducted among the member of the society and it has been very fruitful in understanding the attitudes/views of the members of the society towards the disabled children. Information has been collected in every pre listed village to know about the socio economic condition of the people, and the support mechanism to the disabled, provided by different institutions and the profiles of the different villages.

6. PRA (Participatory Rural Appraisal) TOOLS:

The participatory rural appraisal is a tool for the data collection. It is very helpful in the removal of the professional biasness which creeps in, during any study and its analysis by the experts and the professionals. the various tools of PRA aims at understanding the situations and the problems experienced by the community from their perspective and thus arriving at results which are unbiased and are of the importance for the respondent and the researcher. The PRA necessitates the involvement of the large number of the people from the different backgrounds and proper facilitation by the investigators involving the participation from all members.

SOCIAL MAPPING:

Social mapping is the pictorial representation of the villages. It informs about the health status, sex ratio, socio economic status, Existence of various other institutes like the religious institutions, village committee, SHGs, Anganwadi center, school, colleges, tehsil office, range office etc. which could be the possible organization to provide support to the disabled child. These also give information about the type of dwelling in the village and the demographic set-up of the area and the literacy level of the region .These information are very important while conducting any social study.

CHAPPATI DIAGRAM:

The chapatti diagram is the pictorial diagram about the relationship between various institutes present in the village and the residents. It also throws light on the degree of preference of a particular institute. Since it is a pictorial representation of the facts, it makes interpretation easier.

TIME ANALYSIS:

The timeline is a thorough study about the daily routine of an individual. While conducting the case studies, special caution was taken to note the daily routine of a disabled child which has again been helpful in knowing the kind of support a disabled child gets in his day to day life.

PRESENTATION OF DATA:

Excerpts of the 60 interview schedules have been presented in tables with necessary description of facts & figures. Percentages of the absolute frequencies eliciting in the respective tables gives a proportionate figures of raw data.

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CHAPTER - 4

ANALYSIS OF THE DATA

The field work was carried out in the 28 villages of the Gondia block in Dhenkanal district of Orissa .The sampling done was purposive, in order to cover the spectrum of disabilities and the sample size was fixed as 60 .

The subjects consist of the disorders of:

- Blindness
- Low vision
- Cerebral palsy
- Mental retardation
- Deaf and dumb
- Physically handicapped
- Multi sensorial affected etc

Table. I. Distribution of children with disabilities (CWDs) according to the villages:

Sl No.	Name of the village	Name of the gram Panchayat	No. of disabled child
1	Anandapur	Mathatentulia	1
2.	Bega	Bega	3
3.	Bhaliapata	Kashipur	3
4.	Bellamalia	Pingua	2
5.	B.Karagola		1
6.	Chadakmara	Nihalaprasad	1
7.	Digambarpur	Digambarpur	5
8.	Jambu	Mathatentulia	1
9	Jharada	Sadangi	2
10.	Kashipur kokrajhar	Kashipur	2
11.	Kashipur	Kashipur	1
12.	Kallana	Mathatentulia	1
13.	Laulai	Laulai	1
14.	Lahada	Kashipur	2
15.	Mathatentulia	Mathatentulia	4
16.	Nityanandpur	Nihalaprasad	1
17	Nilkanthapur	Mathatentulia	2
18.	Nuaichhapur	Khandabandha	1
19.	Nuarucha	Mathatentulia	1
20	Santhasara	Santhapura	2
21	Sadangi	Sadangi	8

22	Srimantapur	Bega	1
23	Sologasdia	Ratanpur	6
24.	Phuljhar	Khonkira	1
25.	Palagandua	Sadangi	1
26.	Purshottampur	Mandar	1
27.	Chottatentulia	Khonkira	4
28	Purana Kashipur	Kashipur	1

The above table shows the list of the 28 villages along with the respective Gram Panchayats and the number of cases dealt by the investigators. The maximum number of cases was in the villages of Sadangi, Digambarpur, and Sologadia.

Table.II. Distribution of CWDs according to age groups and sex

Age Group	Male	Female	Total	Percentage
0-3years	2	2	4	6.66
3-6years	4	4	8	13.32
6-9years	10	6	16	26.64
9-12years	6	5	11	18.33
12 to 14	8	13	21	35.30

The above table shows different age groups into which the CWDs have been divided according to the sexes. Around 35 % of the CWDs fall under the category of 12-14 age groups, the next is the category of 6-9 years which accounts for 26.64 %of the total sample. Also the maximum number of children with disability fall under the age group of 6-9 (26.6%) and 12 -14 (35.3%) years of age.

Table.III. Distribution of CWDs according to the family type

Family Type	Number	Percentage
Joint	**17**	**28.34**
Nuclear	**43**	**71.66**
Total	**60**	**100**

Most of the families in this part are of nuclear type and even though some brothers stay together they maintain different hearth for their individual families. The children with disabilities in the region are liable to get support from their grandparents, uncle, aunt and cousins. Thus they have less probability of being isolated even when their parents are busy in the daily chores.

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Table. IV. Occupation of the parents of the CWDs

Occupation	Number	Percentage
Cultivation and farming	12	20
Daily wage earners	25	41.66
Business	2	3.33
Workers and masons	5	8.33
Cultivation with daily wage earning	7	11.66
Others	9	15

The table shows that the Socio –economic condition of the people is very low and a maximum of the people are dependent on the daily wage earning. Nearly 50% of the sampled families live on daily wage labour which is virtually insufficient of providing two square meals for the family members. The child with a disability in these cases is an economic burden for the family and it is very tough for them to get the child medically treated. Only 8.33%were involved as workers and mason workers. 11.66% of the families had there own land but it is as less as 0.5 to 1 acre. The rest 15% are involved in service in governmental and non governmental sector.

Table. V. Distribution of subjects according to educational qualifications

Educational qualification	Number	Percentage
Illiterate	34	56.66
Going to Anganwadi or school	12	20
Primary	14	23.33
Total	60	100

The table shows that 56.66% of the disabled children are illiterate. As per the age group distribution in Table.II, very small proportion of sample (6.6%) falls on the lower age group which scarcely encourages the parents for the schooling of their wards. Hence remaining 93% of the sample is the potential school enrollers who have been denied of education for one or other reasons. Parents do not take care to ensure that their CWDS be enrolled in the school nor are the CWDs themselves interested in attending the classes .There are no itinerant teachers at the school neither do the teachers in the primary or the secondary schools receive any kind of special training to cater to the needs of these disabled children as a result of which teachers find it difficult to treat these disabled children correctly. Even though there is a provision for training of the Anganwadi workers, it is practically insufficient and it needs high expertise and sound training to work with these children. All these results in large no. of dropouts among the CWDS and also that they do not acquire any knowledge even if they attend classes in the Anganwdi and primary schools.

Table.VI. Distribution of subjects according to different facilities availed

Sl No.	Facilities	No. which availed	Percentage
1.	Disability certificate	25	41.66
2.	Disability pension	10	16.66
3.	Aids and appliances	05	8.33
4.	Scholarship	03	5

The table shows that 41.66 %of the CWDs have availed disability certificates. The no. of children who have availed these certificates is larger than compared in ratio to the total population due to the ongoing Sarva Siksha Abhiyan "Education for All" under which disabled child in every anganwadi and primary schools are identified and suitable efforts are taken by the primary school teacher and the anganwadi worker to ensure that the child is certified as a disabled. Also the parents of the CWDs have become aware of this due to the campaign undertaken by the Block officials, the PRIs and the district social welfare office (DSWO) in conducting disability camps regularly at places like Sadangi, Pingua, and Nihalaprasad . However in terms of receiving disability pension the percentage is only 16.66% .Since some of the people do not get the political backing from the PRI members and so they can not get the fixed grant of Rs 100/- on a monthly basis which is given as disability concession. According to govt. figures the total no. of people receiving disability concession in Gondia block is equal to 441 however field studies and experiences tell a different story as indicated in the table. Only 5-6 children of the total children with disabilities have received wheel chairs and tricycles from the block offices which are received in the camps. Once the wheelchair and the tricycle become defunct due to machinery wear and tear, the recipients are not taking care of its repair and further use. Only 1 case with hearing deficit was found with hearing aids although the aids have been mentioned in the disability certificates the disables are not getting it in the camps.

Table.VII. Distribution according to immunization

No. of mothers administered with immunization	No. of child administered with immunization
36	38
Percentage of mothers administered with immunization	**Percentage of children administered with immunization**
60%	63.33%

The table shows that 40% of the mothers have not been administered with all dozes of immunization and 36.66%of the children have also not been administered with immunization which indicates that even now the people are unaware of these preventive care methods in rural areas. In some of the cases the immunization centers were inaccessible for the villagers.In other cases it was only due to sheer ignorance. The cases of mother and children not being immunized were mostly prevalent in villages dominated by the ST population which were located at the remotest of places. A major cause of the disability was the poor health care rendered by the TBA'S/VHW'S towards the expectant mother taking the above issues into consideration. It can only be considered that the CHW'S/TBA'S/VHW'S and the

anganwadi workers are the first line health workers who must receive an up-to-date training towards rehabilitating the disables as well as training the expectant mothers to maintain sound prenatal health care facilities

Table.VIII. Distribution of the subjects according to major type of disability

Sl. No.	Type of disability	No.of children	Percentage
1.	Physical handicap	18	30.0
2.	Mental handicap	11	18.3
3.	Speech and hearing handicap	15	25.0
4	Visual handicap	12	20.0
5.	Multi-sensorial affected	3	5.0
6	Autistic	1	1.7
	Total	**60**	**100**

Out of the total sample 18 CWDS were physically handicapped. These were children suffering from polio, cerebral palsy bilateral CTEV, a condition in which both the legs are bent inwards thus causing a problem in locomotion .Some children also suffered from burns in their hands and legs making them handicap. 11 were mentally handicapped predominated with the problems of seizures,epilepsy, cerebral palsy, slow learners etc.15 were deaf and dumb out of which 3 were found only to be dumb .where as 12 suffered from being visually impaired this included blind children as well as children with low vision. The rest 3 were suffering from multi-sensorial disability. A lone case was identified with Autistic features in the total sample size.

Table.IX. Distribution of children according to events of social ill treatment

Sl No.	Events	No. of CWDs experiencing	Percentage
1.	Name calling	49	81.66
2.	Ignorant behavior	25	41.66
3	Not welcomed in social gatherings	6	10

A child with disability in the rural areas does have to face events of name calling and ignorant behavior by the members of their society. A very common thing observed by the investigators was the event of name-calling. More than 80% of the cases experienced events of name calling like beda, chota , howla, and handappa not only by the members of the society but also by their own family members. The grandparents and the senior members of the society were the worst culprits although they were the key source of support for the CWDs. Name calling is very much prevalent by these grandparents when compared to anybody else. The CWDs studying at schools were the worst sufferer of the event for he/she was harassed collectively by the school mates. It is noticed that name calling has been accepted by the CWDs & their family members when is addressed in normal tone. But when it is extensively teased by the peer groups with some discrimination in play ground or other public places, eventually hurts the children with disabilities, causing their aggression & crying.

However, in the rural India a CWD is not welcomed in the social gatherings contrary to the urban area. Ignorant behavior towards the CWDS is also less prevalent and mostly is reported among the cases with MR, deaf and dumb and blind. Out of the total sample, cases with hyperactive and violent behaviors are not welcomed by the relatives and the neighbors in the social get together and gatherings. Due to hyper active behavior often they have been thrown out from the place or the parents have been offended by relatives.

Table.X. No. of children who received medical treatment

Sl No.	Category	No. of children who have undergone medical diagnosis or treatment	Percentage	No of children who have not undergone any diagnosis or treatment	Percentage
1.	Deaf and dumb	7	11.66	5	8.33
2.	Blind and low vision	9	15	3	5
3.	Mentally retarded	5	8.33	2	3.33
4.	Dumb	1	1.66	2	3.33
5.	Cerebral palsy	2	3.33	2	3.33
6.	Physically handicapped	17	28.33	1	1.66
7	Multi sensory disability	3	5	0	0
8	autistic	1	1.66	0	0
	Total	45	75	15	25

Table.XI. Type of treatment availed

Sl. No.	Type of treatment	No of CWDs	Percentage
1.	Allopathy	45	75%
2.	Homeopathy	4	6.66%
3.	Ayurvedic	10	16.66%

Some of the CWDS in this area have undergone medical treatment for a very short span. 75%of them have been taken to the govt. hospital at Dhenkanal and the PHC at Barapada for diagnosis and medical treatment. 25% of them have never undergone any medical treatment or diagnosis. Only 6.66% of them have availed homeopathy treatment. 16.66% have availed Ayurvedic treatment rendered by the village quacks. Only 1 or 2 cases have undergone highly specialized form of treatment such as physiotherapy .8-10 cases have undergone all sorts of treatment during the onset of problem. In a later phase when expected result of treatment was not seen the parents discarding it switched over to other mode of treatment.

Existing circle of support for autistic and disabled children in rural areas as identified in the rural areas as by the chapatti Diagram

There are various stake holders providing social, emotional, and financial support to CWDs in rural areas. Some of them have been identified with the help of PRA exercises by the investigators which are listed as below. The PRA tool used by the investigators was Chapatti diagram and the people involved in the exercise were

1. Parents of the disable children
2. Member of the Panchayatiraj institutions
3. Villagers
4. Other government officers

Analysis of Chapatti Diagram:

- ***Family the pillar of strength for CWDs***

  The families of the CWDs face enormous difficulties in looking after their disable child and most of the time the support they provide, goes unrecognized by the society. Families deserved a better deal. A majority of children are born with disabilities or acquire disabilities in their early years the family members in the rural area are uneducated and they run from one doctor to another and from one specialist to the next without any precise understanding of their Child's problem. In case of the parents of a mentally retarded child the mother becomes the care taker of the child. The child is rendered functionless due to the disability and also because of no proper rehabilitation and in most of cases the child is even not capable enough to attend to his daily duties. It is the mother to take care of the child and sacrifices her interest for the child in come cases mother is not able to work out side due to the condition of the child, so that the family's income is not sufficient and results in the misarable economic condition of the family. The birth of a disabled child makes the entire family handicapped. Unlike families with able-bodied members, the presence of a disabled person adds a serious dimension of uncertainty to the future. In some cases the family has even become disintegrated and some of the able bodied member have migrated to other places and restrict responsibilities to send regular money orders. Apart from that the family has to face emotional flaks, dire consequences of name calling and mental and physical harassment of the child.

- ***Friends & Relatives***

  Friends and relatives are important sources of emotional and social support for the CWDs. The children with disabilities like mental retardation and blindness don't seem to have any friends as observed in 95% of the cases by the investigators. However they seem to get considerable amount of emotional support from the relatives. Other CWDs with less severe disabilities like speech impairment, visual impairment, and loco-motor disabilities do have a good number of friends with whom they spend time and are intimate to the same degree as is the intimacy seen in friendship between two normal children.

- ***Role of Government & Govt. Agencies***

  The Govt. of India through the district rehabilitation centers continue to provide a package of rehabilitation services to the disabled person in rural and remote areas under the scheme to promote voluntary action for the persons with disabilities. Financial support is being provided to the voluntary organizations for extending services to the disabled.

  Regular disability camps are organized under the SSA (Sarva Sikshya Abhijan). These camps are organized twice in a year. The first camp is held for the identification of the CWDs. For this purpose there is a medical board at the district level consisting of the CDMO (Chief District Medical Officer) and the ADMO (Area District Medical Officer). The camp broadly aims at identifying all the PWDs with the help of the PRI members.

  The second camp is organized for the distribution of various aids and appliances like crutches, blind sticks, tricycles, wheel chairs. The hearing aids are distributed by the District Social Welfare Office. Scholarships for the CWDs are provided directly by the District Welfare Officer. An amount of Rs. 100/-is provided to the CWDs as disability pension on the 15th of every month. Rehabilitation under SGSY (Swarna Jayanti Swarojagar Yojana) is also looked after by the District Administration. Loans are provided under the SGSY Scheme for generating self employment opportunities to extend of Rs30,000/ per disable with a subsidy of 50% under the scheme. 3% of govt. jobs are reserved for the disables. Bus passes, train concessions, and reservations in the jobs are provided by the district social welfare office.

- ***Other CWDs***

  Children with disabilities have an inclination towards making friendship with other CWDs. As observed by the investigators in some cases children with disabilities had another companion who is disabling. There is an emotional bond between two CWDs, even though some of them may not express their feelings to each other. They like to spend time with each other. Parents of other CWDs also help a CWDs by giving useful information to their parents. The father of a deaf & dumb boy at Mathatentulia after admitting his son to a special school at Dhenkanal came back and advised parents of other CWDs to admit their wards in the that special school and also succeeded in his effort.

- ***Government Hospital***

  This is the first place where the parents of most of the CWDs have been after the detection of abnormal behavior of their child. The govt. hospital at Dhenkanal is at a distance of 50-60 Kms. From the home and the rural people do not make an effort to pay regular visit to this hospital as it would mean the loss of daily wages for them. Since most of them are daily wage earners.

- ***PRIs***

  The PRIs are responsible for identifying the disable children with the help of Primary School teachers and Anganwadi teachers. Also the disability concession of Rs. 100/- is made from the Panchayat Office. In some villages however during the field work there were complaints from rural peoples accusing the Panchayat or not helping CWDs whose parents did not politically backed the

ruling member of the Panchayat. The PRI members also extended their support in counseling to the parents of CWDs.

- ***Special Schools***

  Though there are no special schools for the CWDs present at the block level. There were some special schools and rehabilitation centre functioning at the district level. Where the parents of these CWDs can take their children for rehabilitation, education, and training, chief among them are blind schools at Dhenkanal, Jeevan Jyoti, Akshyam Kalyan Samiti at Dhenkanal, NIRTAR at Dhenkanal & Olatpur , Santa Memorial Rehabilitation Centre at Bhubaneswar, Chetana Institute for the Mentally Handicapped at Bhubaneswar etc.

- ***Red cross Society***

  The Red Cross society provides the funds for the purchase of aids and appliances to be distributed amongst the various CWDs in this area.

- ***NGOs***

  NGOs role in the Gondia Block of Dhenkanal District is restricted to counseling and arranging cultural activities for the CWDs. Apart from this some NGOs were actively involved in the arrangement of camps for CWDs and a CBR (Community Based Rehabilitation) programme was also conducted for the blind people by NYSASDRI which is the leading NGO in this area. Other NGOs working for the disable in this area are ISWAR, PIPAR, SRADHA, AHIMSHA, AIRA, etc.

- ***Religious Institutions & Leaders***

  Very less in number as observed by the investigators provide emotional support and peace of mind to CWDs and their parents.

- ***Anganwadi & Govt. Schools***

  The Anganwadi worker helps in the battle against disability due to polio by creating awareness among people. The Anganwadi worker is also responsible for identifying CWDs. She also does the job of counseling the parents of CWDs about camps and certification of their child as a disable. In the school run by the anganwadi CWDs ranging between the age of 3-6 years get education. She also acts as a catalyst for the prevention of disability through adequate antenatal care of nutrition, immunization, etc.

- ***Corporate***

  A Tata Steel Express Train (Jeevan Dhara Express) especially for the treatment of disable ran through Orissa in which many parents of the CWDs from the Gondia block had gone for the free treatment of their child. Tata is the only corporate providing such facilities for the CWDs of this remote and rural area.

- ***SHGs***

  Due to the lack of money many of the parents of CWDs can not take their child for medical treatment. With the advent of the concept of SHGs it has become easier for these people to borrow money to take their child for medical treatment. There are a number of cases seen by the investigators, in which the mother or any other female relative of the child had taken loan from SHG or a Bank for treatment. A few had also borrowed money form the local money

lender but it was not a feasible option for the rural poor since he charges of very high rate of interest.

Although a lot of Govt. schemes and policies have been farmed to support the disabled, there is a great lacuna when it comes to the implementation of plans and policies and only a part of the actual services reach to the grass root level.

Parents of CWDs in rural area are mostly unaware of the govt. services. Majority of them do not even know about the process of certification. 70% of the parents of the CWDs interviewed were daily wage earners and even have been sparing out a day from their schedule for the diagnosis of their child means a loss of daily wage, which ultimately resulted in starvation of family on that day. Apart from that, district hospitals are at a fair distance from their villages and a considerable amount of money is spent on travel which further discourages them from taking their child to the hospital. Mostly in these places people are of the view that disability can not be cured, further they do not have any knowledge about the rehabilitation centers and efficacy of rehabilitation service. Another fact is that the family does not want to part from the disable child due to the feelings of over protection. As a result of all these factors the child's future is left uncertain in the hands of fate. The superstitions that prevail in the society regarding disability are that it is as a result of parent's sin in previous birth and as an effect of lunar eclipse. Politicians and govt. officials grab large chunk of the funds allotted for the disable people with the result that only the part of fund reach to the poor and needy.

There are no itinerant teachers at the school neither do the teacher in primary or secondary schools received any kind of special training to cater to the needs of CWDs . As a result teacher finds it difficult to treat these CWDs correctly.

SOME SELECTED CASE STUDIES:

CASE STUDY NO: 1

Name: Jitan Tarai

Sex: MALE

Caste: SC

Age: 2yrs 3months

Socio economic status: Low

Type of disability: Mentally Retarded with DDMS/CP

Jitan tarai is 2years and 3 months of age and suffering from mental retardation since his birth. jitan's mother had a normal delivery in the presence of a TBA however during pregnancy she was suffering from malnutrition and anemia. After 13 days of jitan's birth Jitan had an attack of jaundice and after 1 year seeing that jitan was not behaving as a normal child his parents took him to a government hospital in Dhenkanal. The doctor prescribed them some medicines and assured that jitan tarai would be cured but his parents due to their low income could not afford to continue those medicines after a certain period of time.

Jitan's parents have a very positive view about their child, jitan's father pitavas tarai said that he did not care if anybody passed a comment on jitan .pitavas's mother was not on very good terms with Pitavas's

Wife and it was she who usually teased pitavas and his wife saying that jitan was a curse of God upon them. Jitan's father said that he did not reciprocated to his mother's behavior .the relatives and the members of the society were not too much interested in jitan and his disability. It was jitan's elder sister who used to spend most of her time with jitan .jitan's elder brother was not very much interested in jitan ,even though he said he would not like others calling his brother by name. His parents said that they were very uncertain regarding jitan's future .no other community members were found who were willing to spend their time with jitan. The child recognizes parents and other family members .He responds to his name called by others but cannot chew food properly. Drooling is also evident, mother takes care of his activities and the elder sister often acts as the care taker .She sacrifices her play time for the sake of younger brother and is desperate to see any improvement in him. Jitan sleeps for very less time during the night and sometimes he sleeps for less than 2 hours he cannot sleep properly and his head bends backwards while he tries to sit .if made to lie down on his stomach he cannot turn and lie on his back the parents do not know anything about the rehabilitation process of the mentally retarded persons and are discouraged to take any step due to lack of money. They do not even know about the disability certificate issued by the government of India.

CASE STUDY 2

Name – Kalpana Behera

Sex – Female

Age – 11

Caste – SC

Socio-Economic Status – Low

Type of disability – Deaf and Dumb

Kalpana is an 11 year old girl, deaf and dumb since birth. Kalpana's mother during her delivery had a normal delivery in the presence of a TBA but during pregnancy her nutrition intake was not adequate. While the parents of Kalpana Behera did not confess that name calling for Kalpana was prevalent in the society, it was very much prevalent as observed by us while talking to the villagers. People do not directly address her as Jadi (which means dumb in Oriya) but while talking amongst themselves, they called her Jadi instead of calling her by her name. Kalpana can understand gestures made by hand to her, her mother and one of her friends named Milli are the best person to understand gestures made by her and to make her understand the gestures. The girl Kalpana goes to school and does not face a lot of problems while going to school since transportation of vehicles is almost negligible within the village. The girl lacks confidence ,is shy, and does not try to give vent to her feeling, even though it seemed she was curious to know about what was happening during our session of conversation with her father and mother. Kalpana wants others to protect her and does not want to be independent judging by her body postures. Kalpana's parents are uncertain about her future as are the majority of the parents of the disabled children. Many do not like to vision the child's future and do not aspire for any betterment of the child. The main reasons for this may be the lack of money, lack of awareness, and the always remaining satisfied attitude. Kalpana is very intimate with her grandmother, and it is her grandmother who pampers her the most. According to Kalpana's mother it was Kalpana's grandmother who's over affection and love had caused her to become a spoilt child. She gets angry at the slightest excuse, and also at times fights with the elder brother. The elder brother does not retaliate and he also sympathizes with her disabled state. In the ultimate analysis, we found out that due to overprotection by the grandmother, father, and siblings, she is content with whatever she has and therefore does not strive for anything more. The villagers also help her in day-to-day activities like going to school, and guiding her while something happens which she is unable to comprehend. The headmaster of her school is her favorite teacher, who sympathizes with her. She helps in the household work, but only occasionally. Her parents wish that after growing up, they will try their best to get Kalpana married but are not taking any initiative to send her to special schools and for further medical treatment.

CASE STUDY 3

Name – Prasanta Kamara

Age – 8

Sex – Male

Caste – SC

Socio-Economic Status – Low

Type of disability – Physically Handicapped (Polio)

Prasanta is a 8 year old boy suffering from Polio despite the fact that he was provided the Polio dozes at camps as told by his mother. When Prasanta was 3 years of age, this disability started to take form, which was characterized by swelling of feet and high fever. On taking Prasanta to the doctor, the doctor declared that Prasanta had Polio and no medical treatment was possible. The parents despite of this kept on trying and spent Rs 20,000 on his treatment.

Prasanta spends most of his time by playing with normal kids, he plays cards, and pebbles with the normal kids. He is very confident, but shy. He can crawl on the road for long distances. He goes to the school crawling on the road, and sometimes it is his schoolmates and his teacher whom he loves the most, who picks him up from his house and drops him to the school. Prasanta himself is very careful while traveling on the road, and tells his brother regularly to walk on the left side of the road. He spends most of his leisure time watching TV, and does not seem to be very much depressed with his present condition. His mother is literate and is a sensible lady and tells him that her plans for Prasnata's future was that she would name the major portion of their property in Prasanta's name so that he would not have to be dependent on his brothers. They were planning to open a shop for him. Prasanta himself is a very good student. Prasanta has 2 or 3 good friends also who are normal but most of the time he spends with his elder brother. The family shows no signs of overprotection and this has resulted in good development of the child, with the child even helping in household activities, like bringing water from the nearest well. He receives a monthly concession of Rs 100 from the government for being orthopedic ally handicapped. The boy is shy, but confident and can do many things like standing with the support of a bicycle, etc. He is very popular in the village and all the neighbors love him for his cheerful nature. According to his mother he is an avid listener of songs and also watches TV very enthusiastically.

CASE STUDY 4

Name – Srikanta Dalie & Satyajit Dalie

Age – 14 & 12

Sex – Male

Caste – SC

Socio-Economic Status – Low

Type of disability – Mentally retarded (Epilepsy, Dyspepsia)

Srikanta Dalie and his brother Satyajit Dalie both are mentally retarded since birth. However the degree of retardation for both of them is different. Srikanta is more severely retarded than Satyajit, and both behave differently under the same situation. Srikanta cannot do anything on his own. He needs the help of his mother or any other person for doing different activities, but Satyajit can eat and drink water, and also dresses his own self without any assistance from his mother. Satyajit and Srikanta have two more brothers who are normal, but both of them like Satyajit more than Srikanta. While Satyajit loves to watch TV, and listen to music, and see Jatras, Srikanta keeps on sitting for the whole day without actually doing anything. One thing in common with both of them is that they get angry very quickly and Srikanta reacts by beating people close to him and Satyajit reacts by throwing whatever he gets at others. Satyajit is very fond of music and if any cultural function goes on in the village, he slips away from his room and goes to see that. For this reason, his parents keep him locked in a room whenever there is a cultural function going on in the village. Both of them respond to their names, only the family members and one boy from the neighborhood calls Srikanta by his name while the others called him "handapa", which means handicapped. Satyajit it seems was getting a feel of what was going on during our conversation. Srikanta however seemed to be clueless about the state of affairs. Both the normal brothers said that they loved Satyajit more than any of the other brothers. The neighbors also love him very much. Satyajit and Srikanta can shake hands when they are asked to do so. One normal brother does not want to send their MR Brothers to any MR school or rehabilitation center. The mother says that she was not sure whether anybody else other than the mother would take care of her children in such a way as she does and was apprehensive in sending the children to rehabilitation centers. The father's opinion was that till he works, he is going to feed his children and after he completes his time, he is going to leave him to God's mercy.

CASE STUDY 5

Name:Nagen bhutia

Age:7

Sex:male

Type of disability:MR with visual impairment

Socio economic status:low

Caste:OBC

Nagen bhutia is a 7 year old boy suffering from mild mental retardation since birth ,nagen's mother did not administered herself with all dozes of immunization during her pregnancy, and was also in the habit of taking 'gundi' during her pregnancy. nagen's delivery was also a premature delivery which took place in the 8th month .

Nagen is a very stubborn and rigid boy nagen's parents said that when they took nagen to the doctor the doctor declared that nagen had an incurable ailment, and that he had a defective brain coupled with visual impairment .the child cannot see clearly even through small distances as experimented by us during the interview.

When shown the fingers and asked to no. them from as close as 1 feet the child would answer by touching the fingers and then responding .The doctor had also declared that the child was very stubborn and rigid and that the parent's should always accept the child's demand failing which the child may go out of control as a result of this advice given by the doctor to the family till date accepts to whatever he says and as a result have protected and pampered him.

Nagen shakes both his hands while speaking. Nagen is a very good singer and spends most of his time singing songs; he is a very good source of entertainment for all the villagers who always want to hear something from him. Nagen also has this affinity of attending social gatherings in order to eat good food.

Nagen does not listens to anybody in the house ,he attended school earlier for a very short period when he used to go to the school along with his elder cousin sister who was a teacher in the nearby village school but unfortunately she expired a few months back .Nagen was very intimate with his cousin sister but her death did not seemed to affect him in anyway nagen was more or less indifferent to the death of her elder cousin sister .In the family he creates a lot of trouble by doing whatever things he is not asked to do . Nagen also has this habit of going out from the house even during nights when he hears the sound of a microphone or a loud speaker playing .(this is a common feature to another mr child srikanta dalie whom we had interviewed earlier) nagen also has this habit of getting up at nights and exchanging his sleeping places he usually does so by changing place from his mother's side to go and lie down to his elder sister's side of whom he is very fond of.

According to his elder sisters, they beat him up whenever he beats them and nagen reacts to him being bashed up by parents or elder sisters by not eating food and not talking to anybody .nagen do not have any intimate friend, there is another girl in the neighborhood who is dumb and deaf but nagen does not shows too much interest in her .He roams through out the village,and the villagers admire him for his quality of singing . During our chit chat with his parents we felt that he was getting a feel of whatever was happening and was also trying to create a impression by singing songs.

CASE STUDY 6

NAME:Changu guia

Age: 7 years

Sex: male

Socio economic status: low

Type of disability: deaf and dumb

Caste:ST

Changu guia is a 7 year old boy deaf and dumb from birth. His village is largely dominated by the tribal population, who are in the habit of consuming a lot of local liquor called handia. changu's mother also used to consume 5-6 glasses of local liquor called handia when she was pregnant and changu was about to be delivered .the society is very backward in the sense that local people have only just learnt about the polio immunization programme carried out by the government of India and there is no traditional birth attendant present in the village .changu goes to the nearby school run by NYSASDRI to study but his friends say that he does nothing at the school and till date he is not able to write his name he has been attending the school since the last 3 months even though he have not learnt anything at the school he is not reluctant to go to the school changu's parents have never taken him to a doctor or to anybody for medical treatment or for any remedial purpose . On being asked as to why she has not taken changu to the doctor changu's mother replies that she was apprehensive as she felt that the doctor may further aggravate the situation. changu's mother is a member of a SHG maintained by the women of the villages and facilitated by NYSASDRI from where she has received a sum of rs. 3000 out of which she is planning to buy some sheep on being enquired as to why she does not uses the money for the medical treatment of her son she replies by saying that she was concerned over the repayment of the loans .one thing is common about the attitude of the parents of those children who are deaf and dumb is that they are really not concerned over the state of affairs ,they do not usually take their child to the hospital for medical treatment , may be because of the fact that they think that their disability is in no way going to affect their means of livelihood which generally does not demand skills of hearing and speech. Even though the child is deaf and dumb he reacts when he is being teased gives us the suggestion that it is generally a group of people , children who tease him collectively there are many villagers including elders who encourage these sort of activities of collective teasing in the villages. The boy changu spends most of his time with his mother and even his brothers do not entertain him a lot once when we went to the school in which he was present we noticed that although he had not learnt anything in the school he was trying his level best to recite poetries along with his classmates so it seemed he was certainly not lacking in effort.

CASE STUDY 7

Name:ranjita barik

Age: 10

Sex:Female

Disability type:Deaf and Dumb

Socio economic status: Low

Caste:OBC

Ranjita is a ten years old girl deaf and dumb from her birth. According to her mother who was the respondent during our interview the parents had spent thousands of rs. in her medical treatment ,but to no avail and there was no improvement in her condition till finally they gave up because of lack of money her mother told that they had taken money on interest from a local money lender and took her to cuttack ,where the doctor prescribed her some medicines , after having the medicines for 1 month they found out that there was no improvement in the child's health and condition and finally gave up the plans for further medical treatment according to one of her elder sister s the only remedy for ranjita was death ,and she told that everybody would be happy after that .she also had been trying to convince her mother to send the child to a dumb and deaf school or a rehabilitation centre since ranjita is a very hyper active child and engages herself in a lot of mischievous activities she beats up her younger brother without any cause at times ,also at any instance of name calling or anybody teasing her up she reacts by throwing whatever she gets and in this way she has often injured people at times . While we were interring viewing her mother she even pelted pebbles at us but she was also enquiring about us from her elder sister. Nobody in the village liked her due to her hyper active nature, on being denied anything; she even threatens to burn the house by taking matchsticks in her hand. she does not listens to anybody apart from her father .The parents also got an opportunity to send their daughter to one of the deaf and dumb school at Dhenkanal the suggestion was given by one of the relatives to them to send her to a special school ,but the mother was apprehensive and did not sent her because she thought that her child would not be properly looked after .mother says that the child was a cause of great inconvenience for them ,and not only the family but also the neighbors had grown wary of ranjita's hyperactive temperament .she has no leisure activities and all the while she keeps on roaming in the village ,and keeps on fighting with the children for no particular reasons due to this nature of hers she had no friends and no well wishers and small children and children of her age try to run away at the mere sight of hers .this has further frustrated her and frustration and depression seems clearly written on her face.

CASE STUDY 8

Name:Rashmita patra

Age: 5 years

Sex: Male

Caste: SC

Disability type: Dumb

Socio economic Status: Low

Rashmita Patra is a 5 years old girl who is dumb from birth her father Khageswar Patra is a daily labour .the delivery was normal and no complication were experienced at the time of delivery .Rashmita's parents had registered her name for certification as a disabled , and the information was given to them by the chair person of the village education committee .frequent instances of name calling were present in the village but the child was too small to react to these .the members of the family feel sad when someone calls her jadi which means dumb in oriya the child is less active shy and all the while when we were interviewing her mother she was sitting in her mother's lap .the child has never been taken to the hospital by her parents .the child goes to the nearby anganwadi and is escorted by her mother or father the child has learnt some alphabets and is showing considerable progress in the anganwadi as told by her school companions the school companions said that in the school she did not played to anybody and kept aloof from every body although she used to put in a lot of effort in her studies the parents as in the cases of most of the dumb children are not too much concerned over the future of the child although the child being a girl the mother fears that at the time of marriage the child will have to face a lot of problem and that it would not be possible for her to face a normal life .they were planning to educate her but were apprehensive whether she will become self independent or not.

CASE STUDY 9

Name: sanatan patra

Age: 6years

Sex: male

Caste: OBC

Disability: Dumb

Socio economic status: Low

Sanatan patra is a 6 year old boy dumb since birth he is a very lively boy ,very aggressive, and has been pampered by the mother and other neighbors .even though the respondent which was her mother said that the nutrition was adequate during the time of pregnancy it is really tough to comprehend a good level of nutrition in such a low income most of the people staying in the villages of the GONDIA block are daily laborers working in other's fields and it is really difficult for them to get work on all the days of the month the daily laborers usually work for 20 to 25 days a month which means a daily labour earns anything between 1000 to 1500 RS a month .

Sanatan has a very good friend ,who is a normal child and remains with him always he is also about sanatan's age the 2 spend most of their time together .while our conversation was on with sanatan's mother It was sanatan who brought his friend forward by holding his hand .the normal child is the more submissive of the 2 and it is sanatan who is the more dominant o judging by his body language it seemed as if sanatan was very excited about whatever was happening between us and his mother when we were filling up the inter view schedule .the boy sanatan goes to anganwadi to study but have not learnt anything and keeps on sitting mum in the anganwadi he is till now not able to write down his name .there are instances of name calling in the society and the child sanatan reacts by pelting stones ,at them beating up juniors and by showing his tongue .according to his mother the members of the society get a lot of pleasure in teasing sanatan sanatan has a small sister who is 3 years old ,sanatan loves him very much and spends most of his time with her playing with her and fondling her sanatan has never been taken for medical treatment.

CASE STUDY 10

Name: Srimati hansda

Age: 12

Sex: Female

Socio economic Status: Low

Type of disability: Spinal cord Injury

Srimati is a 12 year old girl suffering from spinal cord injury since she was 4 years old. When she was 4 years old she tried to lift a bag of cement and suffered injury in her spinal cord due to which she has till now stunted growth and her body has not developed in proportion to her age .she sits for the whole day after coming from the anganwadi and watches other children play .she has got a very good friend lakshmi who is a normal child.

She is also her neighbor with whom she goes to school .lakshmi says that while all the children play she sits with srimati and talks with her so that she does not feel hurt. There are instances of name calling for lakshmi ,they are small children of the village and also in the anganwadi where she goes who indulge themselves in name calling .srimati's mother has expired a few years back , and now she spends most of her time with her grandmother .the elder sister considers srimati as a burden on the family and does not hesitates to say it in front of shrimati it seems she has developed a kind of repugnance for srimati since it is she who has to help her in her work srimati cannot sleep properly and has to sleep sidewise in order to avoid the pain the parents are not too much concerned with the present situation and are not taking any initiative for further medical treatment srimati goes to the school and have less knowledge than her class mates the chair person of the village education committee is one person who tries to encourage srimati by saying that she should always try to do well with her studies and academics and that she was in no way inferior to her classmates .continuous reminding to the disabled children that they are not inferior though given in the right earnest is sometimes channelize in the wrong way and the disabled child at sometimes or the other interprets the suggestion in the wrong way and starts building an inferiority complex within himself or herself however there may be children who may interpret these encouraging words in the right way and use it properly to bring the best results .in this case however srimati does not seems to be encouraged by these words she is frustrated with her present condition and tries to overcome it ,another point is that in villages like phuljhor where there are not many disabled cases the children with disability consider themselves to be more socially unfit than those children who see a no. of cases around them and mix with othr disabled children .

CASE STUDY 11

Name: Vivekananda barik

Age: 13years

Sex: male

Caste: sc

Disability type: Moderately Mentally Retarded with Deafness

Vivekananda is a 13 year old boy suffering from moderate form of mental retardation as specified in the disability certificate issued by the CDMO the disability as specified in the disability certificate is 80% Vivekananda's mother faced stiffness in her body during pregnancy and the day before the delivery the stiffness increased very much according to her .

Vivekananda has been taken to the doctor for medical treatment several times .Vivekananda's mother did not administered herself with all dozes of immunization during her pregnancy ,because according to her at times she did not had the knowledge of the dates and also because the immunization center was very far away from bhaliapata .

Vivekananda is a shy boy and when asked to shake hand at the beginning of our conversation he said that he felt ashamed and was not ready to shake hand .although Vivekananda goes to the school he have not learnt anything, he is not able to do anything on his own except taking bath ,he takes bath for long periods of time and continues bathing until someone stops him from taking bath he is very moody in this regard .he cannot speak clearly but can easily give vent to his feelings. he gets angry very quickly and frequently and reacts by beating everybody due to this habit of his there are more instances of name calling for him than usual .the villagers do not show any compassion for him and on being hit by him hit him in return they take the child to his parents and warn the parents to control the child failing which the results would be bad for the child .Vivekananda's uncle said that Vivekananda was a burden upon the family and given a chance they would take him to a rehabilitation center or a special school for the disabled which would also be beneficial for the child in the long run.

CASE STUDY 12

Name: Jyoti Mallick

Age 6 years

Caste: SC

Sex: male

Socio economic Status: Low

Type of disability: Orthopaedically Handicapped (Bilateral CTEV)

Jyoti Mallik is a 6 year old boy orthopaedically handicapped and suffering from bilateral ctev since birth .the child when small could walk by taking the support of the wall or holding the finger of any other individual but could not walk independently, slowly and gradually the child started to lose that efficiency also and was not able to walk with support .after that the parents took him to NIRTAR at Altapur for medical treatment and after paying a no. of visits to the doctor at Altapur the doctor recommended a operation for the child which would cost the family a hefty amount of money and the doctor assured them that the child would become fit after the operation was carried out .the family collected the required amount by selling there livestock and gathering money finally the operation was conducted and at present the plasters are on the legs of jyoti and t the plaster will be removed on the 20th of this month the family members are hopeful that the child will become fit after the plaster is removed , but also say that if the child does not recover they will again spend money on the medical treatment of the child . The child has received a medical certificate and the nature of his disability mentioned is permanent and the percentage of disability is 50%,although the child has received the disability certificate , the family is ignorant about the facilities provided by the govt,panchayat and the block offices .the mother was suffering from blood deficiency at the time of pregnancy and neglected food the child is shy and goes to the nearby anganwadi for studying he has learnt some alphabets of oriya and can read and write the child is in the habit of going to temples and enjoys being there a habit which has been inculcated in him by his father's elder brother, he loves to attend kirtans at the village temples and joins in the group with great enthusiasm .the future plans of the parents ,although the family is very optimistic about the fact that the child will get well after the plaster is removed are very concrete in the sense that they are going to drop the child to the nearest ashrama after there death so that the child can lead a better life over there and does not starves to death they donot have any intention of a capacity building approach for the child since they think that any form of such initiative will require a lot of money and that there financial condition does not allows them to spend any money now as they had already spent a lot of money on the child's treatment.

CASE STUDY 13

Name: Shiba Prasad Pradhan

Village: Bega

Age: 14years

Caste: st

Socio economic status: low

Type of disability: lame

Sex: male

Shiba Prasad pradhan is a 14 year old boy suffering from loco motor disability since birth he and his parents are of the view that it is polio shiba Prasad pradhan was not administered polio dozes during childhood he walks with the help of a stick shiba Prasad pradhan studies in a govt. school which is at a distance of 1and a half km. from his house he is in procession of a disability certificate and receives RS 100 from the block office as disability pension .Shiba Prasad takes the 100 RS. from the block office and does not hand it over to his parents he spends the amount he receives as he wishes he also told us that he was given an advice by an old member of the village to develop the habit of saving a part of those 100 RS. So that he can use it for some productive purpose in the future .Shiba is a very good student and has received a tricycle from the govt, but shiba says that he prefers walking with the support of his stick than riding his tricycle shiba also said that for most part of the day he is on his own ,he sits at the public places and gossips with the villagers .during our conversation he also told us that he has a very good friend and that he was a normal child .both are very good friends and are in the same class in the school. both of them share jokes and study jointly and are good rank holders in the class .

Shiba is a very soft spoken boy another quality in him which makes him affable and admirable to the rest of the villagers the villagers support him with all types of help ,whenever necessary including dropping him to school on their bicycle if required but according to shiba Prasad he prefers not taking help from anybody and wants to be independent in his life .shiba loves playing cards and during the summer holidays he spends most of his time playing cards with the other children and even the older people of the village .his parents have a very meaningful vision about shiba they are planning to teach the tailoring skill to shiba so that he can become self sufficient and than planning to buy him a sewing machine so that he can sustain himself in the long run

The tricycle received from the govt has since than been defunct and the family has no plans of repairing it since shiba prefers going to the school on his feet with the help of a stick Shiba however has different plans for himself he says that he was planning to under take a business in which he will get things from a market and than sell it in the local market and than establish a shop for himself he is very confident that he will do well in his business and has dreams off becoming a rich man.

CASE STUDY NO. 14

Name: Bhagya lakshmi Nayak

Village:Laulaui

Caste: general

Age: 6

Sex: female

Type of disability: cerebral palsy with convulsions

Nirupama Nayak is a 5 year old girl suffering from cerebral palsy with convulsions since birth the child's delivery was very complex and the mother neglected food during pregnancy. There was lack of vitamin and low blood level according to the mother she did not felt hungry during pregnancy and often used to have only 1 meal per day. The delivery was caesarian in hospital in the presence of a doctor in Cuttack. Her mother was mentally very tense during the pregnancy because of the cyclone that took place in Orissa, and the child's birth was only after 11 days of the cyclone that hit Orissa in 1999. Also, when the mother was being taken to the hospital in Cuttack in a vehicle, she had suffered plenty of jerks which further aggravated the situation according to the doctor. Also after 3 days of the delivery the mother and the child both suffered from jaundice which continued till 1 month. The child has difficulty in sitting straight, standing, and walking. She has behavioral problems and is very stubborn and aggressive. Also, she is very emotional. There have been delayed developmental milestones for the child. The cognitive abilities of the child are not fully developed. She is capable of recognition, aware of hunger, thirst, and sleep, aware of toilet activities, aware of needs and speech. Mode of communication is mainly though verbal mood and she comprehends, the verbal command, eye contact and social smile are present.

The child is pampered by her grandmother and grandfather, and the family has also got a reasonably well to do financial background. The family has also tried ayurveda, and homeopathy treatment. The child is an avid watcher of television and can easily say whatever programme is being broadcasted on the T.V. She has got an exceptional remembering power, which easily defies her state. It is the mother who gives her company always. The young brother also lovers his sister very much and is no mood to part away with her younger sister eve if anybody wishes to take her to a rehabilitation centre. However instances of name-calling are prevalent even over here, and the culprits are the grandmother and grandfather. Our intention is not to belittle the love and affection shown by the grandmother and grandfather who by any yardstick of measurement are the most compassionate and emotional companies for the disabled other than the parents, but judging by the same yardstick, we observe that it is generally the grandmother and grandfather, and other elders who are more in the habit of name-calling than any other members of the family. There have been improvements in gripping, speech and balance of the child, and the doctor has further prescribed 1 month of physiotherapy treatment for the child at Cuttack. The parents are hopeful that the child will get well soon.

CASE STUDY 15

Name: Tuni Dash

Age: 14

Sex: Female

Caste: General

Type of disability: Blind

Tuni Dash is a 14 year old girl who is suffering from blindness since she was 10-12 day so age. According to her mother she was normal for the first 10-12 days when slowly the eyes started getting red due to inappropriate medical treatment by a local village quack. The eyes got closed, the family realized that they had done a mistake and then took the child to Dhenkanal on further medical treatment. Treatment in Dhenkanal government hospital, the eyes gradually started to open, but they turned white. Further medical treatment by an eye specialist and application of prescribed eye-drops by him lead to only slight improvement in her vision. After that due to the death of her father, the family could not continue further medical treatment. Some years back she was even sent to a blind school nearby, but inappropriate care and attention shown at the school, and unhygienic fooding and living conditions caused her and her friends to feed away from the school. Since then she is staying at her house. She has a mixed experience of her days at the blind school. She lived a good life according to her and that she also had some friends over there, but she told that the care was not adequate and that the students were not treated properly. She has received a disability certificate at the camp held in Pingua. The family of Tuni Dash holds the NGO (NYSASDRI) in very high esteem because it was during the CBR of programme conducted by NYSASDRI for the blind that the family received tremendous moral support and counseling for their daughter from the voluntary health workers of NYSASDRI. The girl is very soft-spoken, and is very grateful to all her relatives for supporting her in whatever way they have done, but frankly speaking she said that she did not like being helped very often. If she is provided with help, very frequently she gets irritated and even gives vent to her feelings. She says that thought the family helped her, she could see a very slight vision and that she was capable of doing her own work. She had great affinity towards singing songs, and attending Jatras, and also watching TV. During the Biklanga Bandhu Sammitani conducted by NYSASDRI, she even sang a song. The child that is Tuni is being continuously bullied by one of his elder brothers and sister-in-law. Though Tuni was very tactful in revealing this so as not to make them feel offended. During the pregnancy of her mother, her mother did administer with all doses of immunization but the nutrition was inadequate. Her mother suffered from lack of blood deficiency and was also in the habit of consuming gundi. The events of name-calling were less prevalent for her. Mostly it was present in cases of elder relatives but there was no case of harassment by smaller children of the villages. She also said that she wanted to continue education but there was no blind school fro the children apart from the one where she was sent which was bad according to her. She was also advised to wear a contact lens by a doctor but the family feared the glass would affect her eyes adversely. Tuni had a very good friend who was a normal child and also of the same age as she is, but she has since moved to another village and does not come to the village to see Tuni. Tuni repents this fact that she does not anymore come to see her and she

does not also want to trouble every family member by asking them to spend their time for her. She is very friendly with the small kids of the neighbors and they also like her very much. They call her didi and help her in whichever way they possibly can. Tuni spends most of her time wither them by playing games.

CASE STUDY 16

Name: Ani Pradhan Dehury

Age: 14

Sex: Female

Caste: ST

Name of the village:

Type of disability: Blind

Ani is a 14 year old girl who is blind since age of 1 ½ years. At that age an unknown disease affected her eyes and gradually she lost her eyes. At first, the vision blurred and continuously it was lost. Ani and her family are living in acute poverty after the death of her father. There is nobody who is an earning member in the house. The family's only sources of income are the government aids which the family receives in the form of disability pension fro Ani and the widow pension for Ani's mother. At present Ani is residing with her mother, sister, and a brother. She is very suppressive, less vocal, socially withdrawn and of very shy temperament. She hardly feels like exposing her before others. She is isolated in the sense that she hardly interacts with others. At the age of 1 ½ years the parents of Ani Pradhan Dehury depended upon village quacks and local village doctors for the treatment of the child, which led to deterioration in the condition of the eyes and ultimately led to loss of vision. During the presence of Ani's father, Ani was sent to a blind school to Neolpuri where she went with Tuni Dash the case study of whom we have already discussed. Both of them stayed for the same length of time in Neopuri, but where as Tuni learnt to identify a lot of letters and alphabets, where as Ani did not learn any words. They developed a good friendship over there in the blind school and after some time due to lack of care, and protection shown at the blind school, both of them came back together. Neighborhood people address her as "Andha" for which she does not react in any way. She attends her daily activities independently. Mother has no intention to admit her to a blind school since Ani made no progress when she was admitted at Neopuri. The financial condition of the family is very poor. The women of the village were very much concerned about Ani and her family and also during our interview with Ani's mother, they were the ones who were doing the most of the talking. Perhaps the women were anticipating some sort of government or non-government aid for Ani. The cognitive abilities and intellect of such extremely shy children comes to a standstill since they do not interact and talk with anybody and even prefer not to listen to anybody and are always in a world of their own.

CASE STUDY NO17

Name: Pabitra Senapati

Age: 7

Sex: Male

Caste: SC

Type of disability: MR

Name of the village: Bellamalia

Pabitra Senapati is a 7 year old boy suffering from MR since birth. Pabitra has been adopted by his aunt right from birth when she did not had the knowledge that Pabitra was a MR. Pabitra's aunt who had adopted Pabitra was the respondent and she was lamenting about the fact that she had to always remain busy with the boy and had to take extra care for him. Pabitra had a brother who is his best companion. He is also a MR. The two roam throughout the village for the whole day and always prefer in remaining each others company. The child has never been taken to a hospital for medical treatment nor has he been taken to any other place. He has not received his disability certificate. The members of the family say that they did not take him to treatment because they found that there was considerable improvement in the condition of the boy regarding his speech and behavior, and that the clarity in his speech was improving with the passage of time. Although he goes to the nearby school to study, he lacks attention and concentration and lacks behind in studies. He cannot attend to his daily activities. Sometimes he along with his brother goes out to distant places and returns after long periods of time thus causing a lot of tension at home. Pabitra is very stubborn and aggressive andreacts violently whenever his wishes are not fulfilled at his house. The family does nto have any information about the disability certificate issued by the CDMO. The child is hyperactive and shy and does not want to talk to strangers. Also because of poor economic condition they are unable to pursue better medical treatment. Every now and then, she used to blame the politicians that it is they who have grabbed all the funds for the disabled which is being given by the government of India. TO their utter discontent, they say that the Panchayat members and the Sarpanch are not in their favor due to political reasons and that is why they have not rendered them any help in obtaining the disability certificate because they are politically not in favor of the Sarpanch and the Panchayat secretary. However, the family is very optimistic about the chances of Pabitra getting alright and keeps on reviewing his position by their own self. However, they don't have any plans of taking the patient to the doctor because they are discouraged due to lack of money.

CASE STUDY NO18

Name Amina Barik

Age: 4years old

Caste: OBC

Sex: Male

Socio economic status: Low

Type of disability: Autistic

Amina is a 4 year old boy who is a mentally retarded boy and there are indications for him to be autistic however it is very difficult to say whether a child is autistic or not for a layman .the boy's behavior is characterized by the habit of insistence on sameness and remains in a world of his own according to his father and mother he gets up in the night and starts to escape from his house ,he sits in the middle of the road oblivious of the fact that anything is happening around him ,one day a bullock cart ran over him and he did not even moved from his place luckily for him he just came in between the two wheels of the bullock cart and escaped unhurt .he does not even responds to his name and there is another elder sister of his named rti who is also a mr child the parents are more concerned over the fact that the boy is a mr and that he performs such activities that can be extremely dangerous for him rather than the girl being one amina has been taken to the govt hospital at Dhenkanal but there has not been any improvement in his condition although the doctor has prescribed him some medicine he is not able to attend to his daily activities without the help of his mother he is fully dependent on his mother for all the activities he does not utters a single word and does not even responds to his name his sisters are though very fond of their younger brother .

CASE STUDY 19

Name sabita Mani

Age 8 years

Sex female

Caste: sc

Socio economic status: low

Village: kashipur

Type of disability: burnt fingers in right leg

Sabita majhi is a 8 years old girl who has lost her fingers in the right leg due to burns caused in the childhood when she was 7 months old she crawled to the hearth and it was there where she suffered burns in her right leg little sabita can not wear slippers and can not even run she can walk independently but at a very slow pace and prefers walking with a support sabita's mther assists her in going to the school she likes to play games and even plays them with a lot of her friends .sabita's favorite past time is however watching television ,according to her mother sabita gets hooked on to the television where ever a tv is on in the locality for long hours and the people in the locality often tease her for this characteristic of hers .sabita is a very intelligent girl and shows no signs of sub normality of intelligence .she is very quick with mathematical calculations and logical answering the parents of sabita are very proud of their daughter and the neighbors also praise her .students in the school however try to take undue advantage of her disability sabita is not of the submissive kind and on several occasions she has had quarrels and brawls with her friends she says that sometimes some girls push her and run away due to her physical state she is unable to maintain her body balance and falls down sabita is also not afraid to use harsh words against her friends the teacher of the school is also not very supportive although he admires sabita for her intelligence it was infact sabita's school teacher who gave the family information about the disability camp that was organized at sadangi and explained to them as to how the possesion of a disability certificate would help hem in the long run the family had visited the doctor at Dhenkanal and spent rs .5000 on the medical treatment of the child and were in no mood to spend a single penny more for the child sabita has till now not received a disability certificate nor has she received any sort of help from the government sabita behaves quite as a normal child and her disability does not seems to affect her too much mentally ,though she laments the fact that she always wanted to play and run like her other friends do.

CASE STUDY 20

Name:raju behera

Caste: obc

Age: 10years

Sex: male

Socio economic status: low

Type of disability:deaf and dumb mild mr

Village: lahada

Raju behera is a 10 year old boy who is deaf and dumb since birth .the child can not hear and talk since birth .the child's father is a daily labour and earns rs.40 to 50 per day the problem with the daily labour of these areas is tha they are not certain whether or not they will get work on a particular day they earn and eat daily raju behera's parents have not taken special care for the treatment of their son the mother and the child were not administered with all dozes of immunization during pregnancy and after the birth of the child raju behera is a very energetic child he has some very good friends in the village with whom he plays cricket and goes out to see movies and learns dance the child can easily comprehend the gestures made to him by his friends , and his friends like him very much raju does not have any inferiority complex ,he is not shy , he does not suffer from loneliness because most of the time he remains out from his home ,hence he is not over protected from a very small age of 10 years he has got into the habit of consuming guthka and even smokes cigarette .his sister do not like him very much due to his mischievous acts and prefer staying away from him so does raju raju enjoys the company of his friends the most and his friends also love him rather than showing sympathy towards him they treat him like a normal child .sometimes the community members pass negative comments at him but he does not understands it and laughs .whenever he is able to understand the negative comments he scoffs at the individual in his own way judging from the boy's attitude and behavior he does not seems to be very much upset and mentally depressed .he does not goes to the school nor does his parents have any intention of sending him to a school in the future or to any special school .he does not likes anybody helping him out the parents are really not very upset at the present condition of their son.

CASE STUDY 21

Name:sukhodev malik

Age12years

Sex: Male

Caste:SC

Socio economic status: low

Name of the village: Nilkanthapur

Type of disability: visual impairment

Sukhodev malik is a 12 year old boy suffering from visual impairment since the age of 3 months ,although his percentage of disability as mentioned in the disability certificate is 100%,the boy is capable of attending his daily duties ,including bathing independently and do not require any sort of help from any body.sukhodev's mother is dead and he stays with his father nagen ,nagen malik was grudging the fact that many times several people have came to his house and taken information about his son ,they have even promised to help them financially ,but the fact of the matter remains that no one have really helped them in any way from this condition .sukhodev was 3 years old when one day while bathing the lather of the soap went into his eyes and his eyes got closed the parents went to the village quack for treatment but the condition of the eye further deteriorated after his treatment till finally they took him to the govt. hospital at Dhenkanal the doctor at Dhenkanal advised them to apply a eye drop they even started applying the eye drop and there was considerable improvement in the condition of his eyes till they had to discontinue the eye drops due to poor financial condition the family have not received any help from the govt.and the father says that all the funds allocated for the disables are being eaten up by the hungry politicians .sukhodev has a very good friend whose name is nabina both of them study in the same school and in the same class the two boys re very friendly with each other and their friendship is a talking point for the whole village nabina tries to protect his friend from the harsh comments made by other boys and tries to shield him in every possible way .sukhodev's leisure activities includes seeing people playing cards listening to the television and the radio the father is very much concerned for the child's future and says that the child was not efficient enough to do any sort of work that would help him earn his livelihood he also said that he did not knew anything about the special schools that were run for disabled children apart from the one that was near by in joranda but said that the children received very harsh treatment which he said he had learnt from people of neighboring villages and so he had no plans to send his child to such a school .

CASE STUDY 22

Name;Benguli Dehury

Age 2years

Sex: Female

Caste: SC

Socio economic status: Low

Village: Palagandua

Type of disability: Blind

Benguli dehury is a 2 year old girl suffering from blindness since birth, benguli was taken for medical treatment by her parents to the govt.hospital at Dhenkanal they were asked to give an eye drop into benguli's eyes .they started giving the eye drops into benguli's eyes there was an improvement also in the condition of the eyes of the child but they had to discontinue it due to lack of money.

Benguli is very small and therefore the care and attention given to her is the same as given to a small child of 2 years apart from receiving love and affection from her mother

It is her mother's sister who loves her the most and she looks after benguli whenever her mother is not present. social support is not required for benguli since she is too small to seek any kind of social support her elder brother plays and and fondles with his younger sister just as a normal child does .benguli's father works in a private firm and is of the opinion hat he will try his best in order to enable benguli to recover from her present condition and had no ideas of sending her to a blind school

CASE STUDY 23

Name:Ani Nayak

Age: 7 years

Sex: Male

Caste: SC

Name of the village: Bega

Socio economic status: Low

Ani nayak is a7 year old boy, suffering from mental retardation coupled with poor clarity of speech and listening since the age of one year .according to ani's elder brother at the age of one year the condition of ani was not so bad and he was suffering from only mild form of mental retardation with no problems in speech and listening until they took him to a doctor at Dhenkanal the doctor suggested that shock treatment would be given to ani

And after giving electric shock to him he completely lost his speech and since than he is not able to speak. he can not walk properly he cannot even attend to his daily activities without the help of anybody else, and worse enough he does not even

indicate for food when he feels hungry his legs tremble when he stands upon his legs and falls down very quickly his mother assists him all the way in doing his daily activities even though the family know about the disability certificates the child has not received any certificate nor has received any support from the government.

CASE STUDYNO24

Name: Keshab Malik

Village:Santhasara

Caste:SC

Sex: Male

Type of disability: Cerebral Palsy

Age: 14years

Socio economic status: Low

Keshab malik is a14 year old boy suffering from cerebral palsy from birth, according to her mother during the delivery of keshab malik there were a lot of complications and she had to suffer from a lot of pain although the child was delivered at home the delivery involved a lot of complications and she suffered unbearable pain for 4 days prior to the actual day of birth of keshab.

Keshab has problems in holding and his grip is not normal, the social smile is absent ,his hands and legs are crooked and he is not able to walk properly, he requires assistance in almost every activity that he does including bathing ,attending toilets ,wearing his clothes, and combing his hair. according to keshab's mother after the age of 4 months,keshab's situation became more acute and he started facing convulsions which take place till now once on an average in 1monthaccording to keshab's mother the nutrition during the time of pregnancy was not adequate since the financial condition of the family at that time was not good and she used to suffer from weakness at that time .

Keshab do not have any friends the people around keshab including his parents are in the habit of calling him a howla which means mad in oriya and keshab reacts very violently to these type of remarks when his mother and father call him a howla he does not reacts but when anybody else calls him a howla with the intention of teasing him he reacts by pelting stones at them ,and also chases them no ends with his limited capacity he tries to gain sympathy from his father and mother .during our conversation with his father and mother there were also instances of name calling and he was complaining against what was happening. Judging by the events .this was the case in which there were the maximum incidences of name calling. And it kind of enraged keshab no ends for he desperately tries to stop everybody from calling him a howla his parents however do not mind the fact that every body calls him a howla since they are of the opinion that they cannot stop every body from calling him a howla and that even though they felt bad about it there was no way out and that they had to compromise with the situation the family does not attends social meetings and functions due to inconvenience caused by their son there were also the case of other children mentally harassing the child by the other children and it seemed that the

other children derived a different kind of pleasure after harassing him .keshab has received a wheelchair from the block office on the advice of the sarpanch and also receives rs.100 as disability pension keshab's brothers do not like him and do not properly look after him and hate him for his unhygienic ways the father and the mother were very much concerned about the child since they thought that none of the brothers is going to look after him once they die but they had no concrete future plans for keshab.

CASE STUDY NO25

Name: Kabita barik

Caste: OBC

Age 11years

Sex: Female

Socio economic status: Low

Type of disability: Physically Handicapped(left leg affected)

Kabita barik is a 11 year old girl who is physically handicapped due to which she faces problems in working .kabita's elder brother Vivekananda barik is a mr and much of the care and attention of the family is devoted towards him kabita does not faces a lot of problem in carrying out her day to day activities she has been facing this disability since the age of 5 months she was not able to fold her hands and legs and also suffering from high fever which ultimately led to her present state though kabita can do most of his works independently one of the family members always escorts her to any place due to the apprehension of the parents that the child was not capable of independent movement however kabita believed that she did not required always a person to escort her she is irritated of the fact that every time a person is there with her to escort her and that she was a burden for the family .kabita had been taken to the doctor several times but the parents said that the doctor had said that there were no chances for kabita to recover the parents had also taken her to the medical camp for certification as a disabled .the child does not supports the family in carrying any sort of household works when told to do any sort of work she refuses to do so saying that she wont be able to do that work. she spends most of her time playing with her brother who is a hyperactive mr and according to the family the two enjoy each other's company the most. She has been certified as a disabled and her %of disability is 40%which just makes her eligible to fulfill the criteria of being a disabled the parents have till now spent Rs 4000 on the medical treatment of the child they have tried different type of treatment for her including allopathic ,homeopathy, and ayurvedic ,ranging from medical specialists to the village quacks .she studies in a near by school the girl is less intelligent than the other children of the same age group she is a stubborn and a aggressive girl .she says that she does not like any teacher in the school and none of her friends were supportive in the school she was very depressed with her present physical condition and had lost all hopes of recovery .she thinks that there is no one who can help her out from her present condition there are also events of name calling with kabita and the villagers call her choti which means lame in oriya .kabita cries whenever someone calls her lame and reacts by not talking to the family members for long period of time such incidences of name calling often results in

tensions of the family with the neighbors the mother father and the other relatives who live close to their home have high hopes for the disabled daughter they are planning to educate her in order to build up her capabilities and potential they also hope to get their daughter married though they said that they were much more concerned for kabita's MRbrother.

CASE STUDYNO26

Name:Prabhati Dehury

Age: 14years

Sex: Female

Caste: ST

Socio economic status:Low

Type of disability: Visual Impairment

Prabhati dehury is a 14 year old girl who is suffering from visual impairment since birth prabhati has received a disability certificate issued by the CDMO and her percentage of disability is specified as 100% prabhati can see only but slightly during the day and during the night she can not see at all and has to be escorted either by her mother or by her sister.

Prabhati is studying in the nearby school and does not fares too badly in her studies she is an average student .The neighbors around prabhati's house have discouraged her from taking any assistance from any non governmental agencies because according to them one of the NGO which renders its services in the field of medically operating patients of cataracts had been responsible for the death of a local villager who had died after the operation was done .prabhati faces a lot of problem and is unable to lead an independent life .she has never been taken to medical treatment either to Dhenkanal or to cuttack because her mother is not very much concerned about her present state and also because of the fact that there are no male members in the family the family considers it a very laborious and tiresome affair either to go to Dhenkanal or to cuttack .they have only taken her to a certification camp in order to get her certified as a disabled so that they can get the monthly disability concession .it is prabhati's mother who works as a daily labour in he fields in order to sustain herself and her family no body in the school according to prabhati helps her at the time of need including her teacher and her classmates and it was only her elder sister who would always be ready to extend her services to prabhati she desires to play with other children and says that she feels bad whenever she sees children of her age playing but she could not play and run like others since her physical condition does not allows her to do so the mother has no knowledge about blind schools the primary concern of these blind people is food rather than how to go about the treatment of their child prabhati is capable of attending to her daily activities and even assist her mother in doing household works like cooking , seeping the floor and bringing water from the well the girl says that she does not like going to the school and attending her classes it was only due to her mother's wish that she was continuing her education and the atmosphere at the school did not at all motivated her to attend school.

CASE STUDY NO27

Name:Susanta .Kr.Sahoo

Age: 13 years

Caste: General

Sex: Male

Socio economic status: Low

Type of disability: Handicapped (all 4 limbs are affected)

Susanta is a 13 year old student studying in std 8 he is suffering from this state since the last 9 years .it happened with him after a severe fever when he was only 4 years of age since then his parents have taken him to various medical institutions for treatment but all in vain all his 4 limbs are ineffective only finger movements of the hand is possible with the help of which he can write and can hold anything other than that he can not do anything his state is very pathetic in the sense that he has to be carried from one place to another and can not move on his own he has received two wheelchairs one in the disability camp and another from oltapur he can move his hand to put way the flies that were roaming over him his condition is pathetic. however susanta is a very good student in the school his mother is very optimistic regarding susanta's future and is also aware of the various schemes run by the government for the disabled she thinks that the child is academically very good and is liked by his teacher at the school the child is carried to the school everyday on the wheelchair by either the mother or the father susanta's best friend is satyajit another disabled child who is a mentally retarded boy his neighbors are very kind hearted and noble people and susanta gets a lot of mental and emotional support from them even during the absence of his parents susanta considers himself a misfit for the society but his parents do not think so he tries to find a companion for himself in another disabled child although he has no problems regarding speech and hearing and he has no sub normality of intelligence he feels shy to talk to normal people susanta has lost all hopes that he may ever be able to use his hands and legs in his life .

CASE STUDY NO28

Name: Balram Dehury

Age:14 years

Caste: Sadangi

Socio economic status: Low

Disability type:Mild MR

Balram Dehury is a14 year old boy who is suffering from mild form of mental retardation since birth, characterized by sub normality of intelligence and unwillingness to do anything as told by others .

According to his grandfather,balram used to go around the village and play with kids of his age when his mother was alive but after the death of his mother the child has

stopped going outside and he keeps on lying on his bed without actually doing anything .the stepmother is not very supportive to balram and balram and his grandfather stays in a separate house which the grandfather has received under the indira awas yojna .balram feels insecure and is reluctant to talk to anybody he does not listens to anybody and it is only his grandfather who talks to him .The life it seems has become too difficult for him because apart from facing the trauma of being mentally retarded the child has really no one on whom he can depend for emotional support his step brother and sister have developed a kind of repugnance for him probably instilled in them by the mother and do not like balram at all balram does not wants to have his lunch with anybody and prefers having the lunch alone balram's father took him to a hospital at baripada but the doctor declared that balram's condition was incurable and hence they did not took any further initiative for balam's treatment balram does not likes watching tv or attending jatras and says that he prefers remaining alone at the house without any friends he seemed to be lost in a world of his own and keeps mum .for most part of the morning he keeps bathing for long intervals of time he also said that he loved water although he did not knew how to swim balram is very lethargic ,inactive and does not at all likes socializing with people he does not even responds to his name and the social smile is also absent.

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Chapter- 5

Summary of the Findings

The fore going chapters have elicited considerable information on the status of children with disabilities in Gondia Block of Dhenkanal District, Orissa. Despite formulation of numerous policies & Acts for the social, psychological & economic rehabilitation of the PWDs, the desired result of their ultimate mainstreaming in the society as a contributory member is yet to be attained. In rural area the situation become more pathetic because of the ignorance of parents & community regarding rehabilitation service, vocational training, government facilities etc. In spite of the inadequacy of service delivery it is heartening to notice that children with disabilities are managed with care & affection by the family members. Instances of over protection or underestimation of the potentialities of such children by parents has been commonly noticed during the course of investigation. Under exploration of the abilities of CWDs has been attributed due to the ignorance of parents of such facilities/training, which can help them think in aproper perspective of the future of the child. In some cases the parents are putting extra care & attention on such children on a sympathetic drive. Some of the parents also have the opinion of everything will be normalized as the child grow older.

Need of the Child with Disability

From the analysis of the cases it is evident that the need of the child with disabilities as follows:

- The child needs encouragement to play like other children. The child must be played with and talked to just like one talks to and plays with any other child.
- Similarly the child needs to play with other children & needs to communicate with other children, need to take care of him self and needs to get around alone.
- The child needs to participate in the activities of the community.

It is generally recognized that prevention is the ultimate goal of all efforts to combat disability. Disability poses two main problems:-

1. The task of prevention of those conditions which are of biological or socio-cultural origin.
2. The second problem is the amelioration of these conditions wherever possible by the biological, social and educational means.

The most important needs for CWDs from the society is Inclusion in mainstream schooling. What is generally happening in the rural educational system that the CWDs are included in a normal classroom without a well planned support system. This is not inclusion. Services in the rural India that deal with CWDs are very poor and imply a financial and psychological burden on the family and society at large. There is a need for a sense of responsibility at all levels that such help must be rendered to children with special needs.

- Attitude of the Parents, Relatives, and Society

The study reveals that the relatives play various important roles by catering to the needs of the child with disability, there by lessening the burden of the parents and stress in the family. The grand parents for example have been found to be of immense help in helping their special child in the area of social and communication skill. These happen as incidents of daily routine but they have never been given any professional guidance. Perhaps if guidance is given they can assist the CWD in much more satisfactory and useful manner. Study reveals that none of them ever had the chance to talk to professional about their child's problems. They had their own misconceptions, doubts, and worries. Some of the parents expressed their desire to know more information about training and future matters of their child with disability with the view to gives support their desires needs to be fulfilled.

As the child starts growing on, the fear of the future of the child starts haunting the parents. Most of the parents were uncertain about their child's future prospects especially those having a child with mental retardation expressed deep concern, "what after them" the question remains unanswerable. The future for the children of other forms of disability although not very acute and marriages of a male disability is quite common, as viewed by the investigators in the field work.The general attitude and belief of CWD towards the society is different depending upon the environment in which they live in.

A mentally retarded child is generally found to be stubborn and aggressive and one who give vent of his feeling quite easily. These MR children are the ones who are over protected by their parents and mothers in particular. How ever there are few parents who do not show any signs of over protection towards the disable child. Inclusion in the society is difficult for these MR children due to their unpredictable behavior, they do not remain for a long time in schools and Anganwadies. The general attitude of the society towards a MR Child is that of pity and sympathy A mentally retarded child in most cases becomes a source of entertainment for the villagers when they sit in groups; the parents of MR child are the once who are mostly affected by this. Most of the parents however accept these children. Very few of the parents expressed that the disable child was a curse of god upon them however some of the member of the society were of the opinion regarding the same line of thought.

Children with severe form of disabilities like MR, blindness and cerebral palsy were generally considered as a burden on the family both economically and socially. According to these rural people children with disabilities hearing & speech impairment, low vision, etc. were not really considered as critical cases as the people thought that these form of disabilities would not really affect them in their means of livelihood when they grow up. In some cases there was lack of serious efforts on the part of the parents to take these children for medical treatment. However the behavior of the society towards such children is of compassion and of assistive nature. These children show less signs of aggressions and hyper activity as compaired to the CWDs under MR and cerebral palsy category. In some cases the parents did not take their child for medical treatment fearing that the doctor would aggravate the situation.

The medical practitioners in the Gondia block lack expertise and are not able to diagnose the form of disability correctly. They go on the hit and trial method of medical treatment which results in expensive affair for the parent, getting the

slightest of improvement. Some parents disregard the feeling of the disable child and tend to take him / her for granted. There were also instances of parents neglecting a disable child only because the future does not hold many promises for him / her. Although these nos. are very few. Some parents do not believe in investing on the education of disable child while going all out for the other.

This attitude among parents reflects their non acceptance of the situations.In many cases they even opt to have another child in quick succession. Parents of children with MR & cerebral palsy are also uncomfortable for taking their child to public places and to social gathering. The CWDs too start communicating others through the development of problematic behaviors such as pinching, beating, biting, throwing temper tantrums etc. The hyperactive behavior of most of the CWDs is to attract attention because they feel themselves neglected. The parents some times unknowingly hurt the feelings of CWDs and some times tend to take him for granted. For example not asking the choice of a CWD in matters of food and cloth. This sort of events is the cause behind the tendency among CWDs of developing inferiority complex, building a sense of insecurity and feeling neglected. This further aggravates their already disable state.

Also most of the parents expressed lack of confidence in their Child's ability. They considered him / her as a complete misfit for the society. This affects the child mentally although he / she does not normally express it in words. In many cases observed by the investigators, the CWD has expressed his / her desire to prevent their parents to stop them form name calling. There is however certain advantages which are CWD in a rural area enjoyed. A CWD in a rural area is not exposed at every step of his / her life like a CWD in urban area. The events of social inclusion are more prevalent for CWDs in rural area. In rural area people are more homogeneous in terms of money and occupation and therefore a CWD dose not face much of problem in social interaction if he really wishes to do so.

Another important feature of the respondents during the interview was their expectations from the investigators most of them expected financial help from the NGO with whom the investigators were working .The parents of the CWDS were of the opinion that a large chunk of the fund sanctioned for the PWDs by the government is eaten up by the hungry politicians.

Most of these CWDs do not like the help that is rendered to them by others but they have to accept it under force since there is no other alternative. Also most of these CWDs are quite frustrated and depressed with their physical condition. Most of the parents are not only financially unstable but also illiterates. This to some extent couples their problem .The community members manifest sober and sympathetic attitude towards the child. The fact that most of these CWDs (other than the ones suffering from mental retardation) desire to play with other children but their physical condition does not allow them to do so and makes them more frustrated. Because of the over protection provided by the parents and the relatives sometimes these CWDS suffer from emotional blocking and inability to think logically which manifests itself in very crude ways.

The parents of these CWDS do not want to part with their children thereby not sending them to special schools or rehabilitation centers in rural areas there are no special schools at the vicinity. It is situated at a distance of 50-60 kms away from their house which means keeping the child at the school also drains their

money earning opportunity. Due to over protection the family and specially the mother does not want to part with the child. Also families rarely take the trouble of educating their disabled girl .Government intervention is inadequate because the care of the disabled comes somewhat low on their agenda when compared with the more pressing problems of providing food, drinking water, health care, primary education and learning .

There are cases amongst those suffering from severe and profound form of mental retardation where the child is not even capable of attending his daily duties and the mother has to attend him/her at all times. Some of the children were not able to indicate for food when hungry, not aware of toilet needs. There were cases when the child used to get up at night and try to escape from the house, hearing the sound of a loudspeaker. All these behavior of a MR Child demand larger responsibilities from the family and society members especially from the mother. She provides round the clock care for the child who is hyperactive. Emotional outbursts of mothers of MR children were noted during the fieldwork .In the rural society with hardly any support in terms of respite care and adequate rehabilitation services for the CWDs ,the parents have to continually wage a war to go through simple activities of day to day living, say teaching their child to even brush his/her teeth. None of the facilities is available in the rural setting like early intervention, schooling and vocational guidance. So the onus of responsibility lies on the parents generally the mother is always expected to be in complete charge of the child as a care taker. A mother of a disabled child undergoes a lot of emotional turmoil and on the top of it the society expects her to rise to the occasion and take on the challenges without any support services. A mother of a disabled child undergoes a lot of guilt herself, and the society sometimes puts the blame on her. Her physical and mental health is completely ignored .Her life takes a lot of twists and turns for which she is completely unprepared .Even a simple thing like a good night's sleep eludes her for years as disabled children especially MRs can be demanding even in the night even when they grow up .She has to handle her child's tamper tantrums, possible medical conditions, daily routine like bathing, feeding and sleeping, find sources of entertainment for her/him. At the same time her obligations and responsibilities towards other members of the society continue.

- Hurdles & Remedies

Services for prevention, early detection, intervention and rehabilitation in rural India even after 57 years of independence are minimal .Hence there is an urgent need to develop services for the disabled in the rural areas by building up bridges through convergence. The primary concern is the creation of awareness against disability, to remove the myths, taboos, and misconceptions associated with disability in India .The geographical vastness, low levels of literacy, and attitudinal barriers are impediments to awareness creation on many issues relating to disability and rehabilitation. There still prevail many misconceptions and negative stereotypes, which have to be dispelled in order to make the society receptive to the changing responsibilities of partnership in the process of protection of rights and empowerment of CWDs.

Non formal mass communication modes and campaigns have to be encouraged for better awareness in rural areas. To improve the condition of CWDs training is essential at all levels.

CWDs

Competence in literacy, in numeracy, and Sself care skills must be acquired by CWDs at least to the nationally defined level of basic learning. The training must promote physical, intellectual, and psychosocial capacity and also develop values that promote equity, skills to safeguard themselves from violence, abuse and exploitation.

TEACHERS, EDUCATORS

Curriculum development for CWDs requires reorientation of the educators. Educators may include the parents, grand parents and the relatives, professionals, personnel and grass root functionaries who are working in the field of disability and also in other sectors. What actually needed is integration in the main stream. Simply by providing some thing separate with equal facilities is not equal. That is the kind of equality we have to envisage and if we do that, then only we are entitled to say that we have the correct perception. Camp approach has an important role to play for providing services to those who cannot travel long distances for availing the services .A well organized camp approach as is being done for family planning, eye camps,etc.with active government support is proving useful in this context.

Education is vital in allaying the myths and taboos concerned with mental retardation. CWDs have problem like poor attention span, passivity, learning disabilities and behavioral disorders. Hence Individualized Rehabilitation Programme may be conceptualized taking into note of the specific needs. Parents must be made aware by appropriate training programmes of the potentialities of their children & inevitable requirement of rehabilitation service.

Moreover in the rural areas because of the lack of the know-how and the absence of the trained professionals and medical specialist, it is a common thing that the optimal results are seen only when the therapy is started. Before the disorder becomes prominent so the early detection of the disability is very essential to give the child a best possible chance to realize his potential.

Most the pregnant mothers in the field area were addicted to local drug “gundi”and even consumed at the time of pregnancy. Also the tribal women had the habit of drinking local liquor. The consequence of consumption of the alcohol during the pregnancy proves fatal for the fetus. So the counseling of the mothers is also very important.

NGOs have the capacity to substitute the government efforts in the formal delivery of specific services as they are locally based and provide a scope for the beneficiary participation. Their commitment and the empathy to the services is beyond doubting. In majority of the cases the NGO programme are less expensive without the bureaucratic hurdles & are with the direct action in the field. Although NGOs movement in India has increased manifold, there is inadequacy in the capacities available in terms of the number of organizations in various field of social issues when compared to the countries abroad, particularly in the field of disability rehabilitation.

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