CHILDREN AT RISK

Challenging Boundaries

A study on mentally challenged children

Publication	:	Challenging Boundaries: A Study on Mentally Challenged Children
Published by	:	CHILDLINE India Foundation
Research Team	:	Ajitha. R. Manjeshwar, Dr. Abhishek Lakhtakia, Amol L. Jadhav, Ramesh R. Pawar, Sudhir S. Salgar, Vinayak M. Sakhare
Data Analysis and report documentation	:	Ajitha. R. Manjeshwar, Dr. Abhishek Lakhtakia
Editorial Inputs	:	Preeti Bhat, Nishit Kumar, Larissa Pitter
Acknowledgements	:	Mr. A.B. Rajmane, Founder - Principal, Jivhala School for the Mentally Handicapped, Sholapur. Principal and Staff, Jivhala School for Mentally Handicapped, Barshi. Dr. Asha Deshpande, Karve Institute of Social Sciences, Pune. Principal and Staff, Kamyani Prashikshan and Sanshodhan Society, Pune. Ms, Mangala Honowar, coding and data entry. CIF team members
Publication Supported by	:	Plan India
Cover design by	:	Design Workshop
Design	:	Designbar
Printed by	:	Jenaz Printers
Year	:	2008

Nana Chowk Municipal School
2nd Floor, Frere Bridge
Near Grant Road Station, Mumbai-400 007
Email: dial1098@childlineindia.org.in
Website: www.childlineindia.org.in
Tel: 91 22 23881098 / 23841098,
Fax: 91 22 23811098

FOREWORD

CHILDLINE India Foundation (CIF) is pleased to release the “Children at Risk” series of publications. These publications comprise findings of original social research on specific communities of vulnerable children.

Over the past few years, the CHILDLINE Network has reported hundreds of thousands of cases of children in distress. In many cases, we come across cases of children who are trapped in unique situations- situations that not only need to be addressed in terms of statutes but also require special interventions. Children from across the Indo-Bangladesh border, Children in Mining, Mentally Challenged Children and Children addicted to Substance Abuse are amongst these communities. In these groups, rights of children are not only routinely abused but the solution requires cross-support from a number of agencies and ministries. We call these groups “Children at Risk”.

As a distress response network the CHILDLINE 1098 toll-free nationwide service, which currently receives over two million calls a year, our objective in conducting these studies is more to facilitate the attention of organizations that work with such issues to also consider focusing attention on children impacted by these issues.

Our findings suggest that Child Protection initiatives among these children require a deeper understanding of their circumstances and the factors that impact them most in their vulnerabilities. It is to address this need that CIF commissioned social researches. They are illustrative of the issues rather than representative at a national level. By no means are they to be considered as indicative of the size and structure of these communities across India.

We hope to partner with agencies and government bodies in developing intervention solutions to these children. We are very keen to obtain feedback from organizations who work with such children so that we can fashion effective intervention strategies.

Do write in to us.

Kajol Menon
Executive Director
kajol@childlineindia.org.in

EXECUTIVE SUMMARY

"Every child is special". The same holds true for a disabled child also. But not many seem to think so. The "International Year of the Disabled, 1981" shed light on the status of the disabled and drew focus of many countries. The population of disabled in India is estimated to be 90 million and 30 million are children below the age of 14 years. One in every 10 children is born with, or acquires, a physical, mental or sensory disability. India has approximately 450 million[1] child population and the prevalence rate of mental retardation is 0.5 to 1 % (Planning Commission of India, 10th Five Year Plan 2002-2007). There is a lack of data that provides a clear picture of the prevalence of mental retardation in India.

CHILDLINE India Foundation under its "Children at Risk" series study undertook an exploratory study on Mentally Challenged Children in Sholapur District, Maharashtra. The study was done at three levels – District, Taluka and Village. The respondents for the study were parents of the Mentally Challenged children and were chosen through Purposive Sampling method. Primary data was collected through detailed personal (structured) interviews. In-depth interviews were conducted with parents, teachers, principals and professionals from the field. Focused Group Discussion were also conducted with the parents.

The study report is divided into four chapters. Chapter one sheds light on mental retardation and the current status. It highlights the statistics of mentally challenged children, CHILDLINE service and mentally challenged children. Chapter two deals with the study per se; the area, scope and methodology of the study. The third chapter highlights the findings of the study. Some of the key findings are mentioned below:

- In 24 % of the cases of the mentally challenged children, one of the parents was mentally retarded and 18% had a mentally retarded sibling. 58% had at least one close relative in the family (that is the child's uncle, grand parent etc) with a similar condition.
- 11% of the mothers of the mentally challenged children were below 18 years and 3% were above 36 years at the time of conception.
- 36% of the mothers reported complications during pregnancy ranging from asphyxia, abnormal delivery, umbilical cord wound around the neck, prolonged delivery and use of forceps.
- 41.2% of the mothers reported being under severe stress during the course of pregnancy.

1. As of year 2005 based on Census 2001 and UNICEF Statistics

- 50% of the parents realized their child was mentally challenged when the child was showed delayed milestones such as crawling, walking, talking etc in comparison to other children of the same age.
- Only 4% of the parents were aware that their child has rights.
- 38% of the children had attended classes up to standard I, 15% up to standard IV and 8% up to standard II and VII respectively in a normal school.
- 15% of the parents reported being unhappy with their child's school citing reasons such as no special teaching, improper teaching and no improvement in the child after joining the school.
- 25% of the parents wanted better facilities in the school such as specialized teachers, more interesting and interactive modes of teaching, and provision of hearing aids.
- 25% of the respondents believed that their child would be a hindrance in the wedding of their other child/children due to the stigma attached to mental retardation.
- 80% of the respondents involved the child in social gatherings such as weddings, family functions, village festivals etc.
- 33% of the respondents did not let their child socialize and interact with other children for fear of being teased by other children, accidents, aggressive behaviour of other children, fear of animals, and no control over bowel and bladder movement.
- 75% of the parents expressed their expectation from the helpline services such as emergency/medical treatment, teaching/recreational/guidance & support services, financial assistance and help in tracing missing children.

The final chapter provides recommendations based on the study findings and the implications for CHILDLINE to work further towards advocacy and protection of rights of the children. Based on the findings of the study recommendations under three broad headings - Programmes and Policies for Protection of Rights, Institutional Support, and Sensitization and Awareness have been put forth. Recommendations for CHILDLINE India Foundation too have been highlighted in the final chapter.

CONTENTS

INTRODUCTION

An 11-year-old mentally challenged boy was tortured by the caretakers of residential institute in Chennai. The child's body had severe burn marks and his knees had festering wounds. The child was rescued by a human rights group. (http://www.thaindian.com/newsportal/health/probe-promised-into-mentally-challenged-childs-torture_10029988.html)

12th April 2006, a fourteen-year-old mentally challenged boy was lynched to death by a mob in Bardaman District, West Bengal. A few days before the incident, the child had run away from his home and was roaming around Tinkonia bus stand. The child was hungry and had taken a biscuit from the nearby tea shop. The shop owner chased the boy. Local people who had witnessed the incident too joined in the pursuit. Fearing the mob, the child had taken refuge in a nearby garage but was chased out by the garage owner. The mob caught the child and beat him up ruthlessly for half an hour and left him severely injured and bleeding. The child died shortly after.

The child's father approached the local police for justice but the police refused to lodge a complaint stating the incident had taken place outside their jurisdiction. No legal action was taken. (http://www.ahrchk.net/ua/mainfile.php/2006/1678/)

On 12th April, 2008, a 12-year-old mentally challenged girl - who has difficulty in both talking and hearing - was allegedly raped by her neighbour in the wee hours in east Delhi.(http://timesofindia.indiatimes.com/articleshow/2950027.cms)

As per a UN report, women and girls with disabilities are particularly vulnerable to abuse. In a survey conducted in Orissa in 2004, it was found that virtually all of the women and girls with disabilities were beaten at home and abused.

In a very recent event, the Maharashtra State Government recommended Hysterectomy for mentally challenged inmates in government-run mental institutions. The government's reasons for advocating hysterectomies was that inmates (mentally retarded adolescent girls or adult women) cannot maintain hygiene and do not co-operate with caretakers. This is an obvious incident of violation of an individual's rights. (www.medindia.net/news/)

Instances such as these bring to focus the state of vulnerability of the mentally challenged and the issue of Child Protection. These are just a few case representation of the plight of mentally challenged children across India. CHILDLINE too has handled numerous cases of mentally challenged children

and has come across hurdles while dealing with these cases. Mentally challenged children, especially the girl child are most vulnerable to abuse. These children are recognized as “Children at Risk”.

The approach towards mentally challenged children appears more as welfare rather than rights based; this in spite of India being signatory to the United Nations Convention on the Rights of the Child (UNCRC).

This study is an attempt to explore the status of the mentally challenged child, awareness of services, attitudes and perceptions. And thereby explore the possibility of reaching out to the children and address the issue of care and protection.

1.1 Mental Retardation: Definition

The terminology Mental Retardation has undergone numerous changes. For centuries different terms were used to refer to Mental Retardation. Mentally retarded people were called names such as idiots and fools. Till the mid-20th centaury, the terms moron, imbecile and idiot were used to refer to the three levels of retardation (highest to lowest). Feebleminded was another term used. More recent terms include mental deficiency, mental sub normality, mentally challenged, children with special needs and differently abled children in a bid to decrease discrimination against these children.

For the purpose of this study however, the terminology used is Mental Retardation or Mentally Challenged, without any prejudice.

In the modern clinical psychology, various sources have defined mental retardation in different ways. The Persons with Disability Act, 1995 defines as “a *condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence*”.

Degree of Retardation[1]

Table 1.1

Sl.No	Mental retardation	IQ Range
1.	Mild	50-70
2.	Moderate	35-49
3.	Severe	20-34
4.	Profound	Under 20

1. Rehabilitation Council of India – Disability Development in India, 2005, New Delhi

According to the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (DSM-IV), Mental retardation (MR) is characterized "by significantly sub average intellectual functioning (an IQ of approximately 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning" (American Psychiatric Association, 1994, p. 37).

DSM – IV, Subcategories differentiated by IQ scores include [2]

Table 1.2

Sl.No	Mental retardation	IQ Range
1.	Mild Mental Retardation	50-55 to approximately 70
2.	ModerateMental Retardation	35-40 to 50-55
3.	Severe Mental Retardation	20-25 to 35-40
4.	Profound Mental Retardation	Below 20 or 25
5.	Mental Retardation, Severity Unspecified	-

1.2 The Current Scenario

The Census report 2001, estimated 21 million disabled people, which is 2.1% of the total population (Table No. 1.1). The latest NSSO (National Sample Survey Organisation) 58th round (2002) estimates about 18 million persons (1.98%) with certain disabilities; the survey has not taken into account disabilities like cerebral palsy, autism, learning disability etc.[3] According to other surveys and reports available the population of the disabled is estimated to be 90 million with an annual increase of 2 million. Of the estimated 90 million, over 30 million are under 14 years. [4]

According to government estimates, one in every 10 children is born with, or acquires, a physical, mental or sensory disability. As per this, India could have 12 million disabled children. It is estimated that 75 per cent of the disabilities are preventable.

Mental health disorders account for nearly a sixth (16.7%) of all health-related disorders. It is estimated that ten million people are affected by serious mental disorders. **0.5 to 1 percent** of all children have mental retardation (Planning

2. http://www.come-over.to/FAS/R54/MR.html
3. Rehabilitation Council of India – Disability Development in India, 2005, New Delhi
4. Rehabilitation Council of India – Disability Status – India, 2003, New Delhi

commission of India, X[th] Five Year Plan 2002-2007). Most countries devote one percent of their health budget to mental health service. India spends just 0.83 per cent (WHO 2001). Lack of facilities, trained medical professionals, and social stigma have always been major hindrances towards the treatment of a mentally ill child [5].

Table 1.3

Disabled population in the age-group 0-19 by type of disability, age and sex, 2001

		Type of Disability				
		Visual	Speech	Hearing	Movement	Mental
Total Disabled Population	21906769	10634881	1640868	1261722	6105477	2263821
Disabled population on 0-19 years	7732196	3605553	775561	90452	2263941	96689
Disabled children as per cent of the total population in 0-19 years	1.6%	0.78%	0.17%	0.01%	0.48%	0.17%
Disabled children as per cent of the total disabled population	35.29%	33.9%	47.26%	23.02%	37.08%	35.19%

Source: Census 2001

The National Sample Survey[6] (NSS) report – Disabled Persons in India, for the purpose of survey defined the group as,'Persons *who had difficulty in*

5. HAQ: Centre for Child Rights – Status of Child in India Inc, 2005, New Delhi
6. Government of India – Disabled Persons in India, 2003, New Delhi

understanding routine instructions, who could not carry out their activities like others of similar age or exhibited behaviors like talking to self, laughing/ crying, staring, violence, fear, and suspicion without reason were considered as mentally disabled'. The reference to "activities like others of similar age" included activities of communication (speech), self-care, (cleaning of teeth, wearing clothes, taking bath, taking food, personal hygiene, etc.), home living (doing some household chores) and social skills.

Findings of the NSS 58th Round

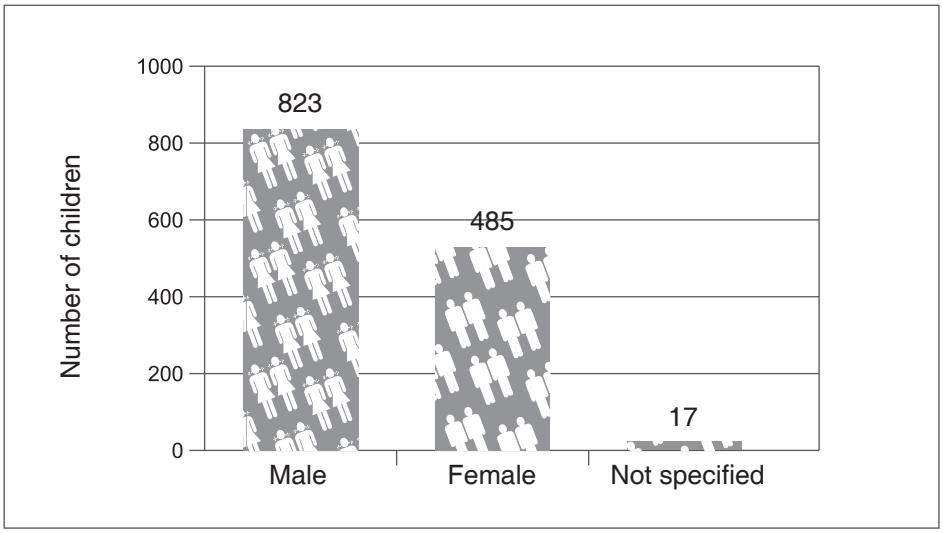
- The number of disabled persons enumerated in rural and urban India was 49,300 and 26, 679 respectively.
- About 8.4 percent and 6.1 percent of the total estimated households in rural and urban India respectively reported to have at least one disabled person.
- The number of disabled persons in the country was estimated to be 18.49 million during July to December 2002
- For every 100,000 people in India, there were 1755 who were either mentally or physically disabled. The prevalence of disability among rural residents was 1.85 percent and among the urban it was 1.50 percent.
- 84 percent of the mentally retarded persons were born disabled.
- About 11 percent of disabled persons in 5 – 18 years age group were enrolled in school in urban India as compared to even less than 1 percent in rural India.

1.3 CHILDLINE Intervention

CHILDLINE is India's first 24X7 toll-free phone emergency outreach service for children in need of care and protection linking them to long-term services for their care and rehabilitation. Any child or concerned adult can call 1098 and access the CHILDLINE service anytime of the day or night. Today, CHILDLINE is operational in 82 towns and cities across the country and has responded to over 13 million calls for assistance since inception.

CHILDLINE has recorded a total number of 1325 cases of mentally challenged children since April 2003. Of the total cases received, 823 were male and 485 female. In 17 of the cases the gender of the child was not specified.

Figure 1.1 Gender wise distribution of calls received on CHILDLINE 1098

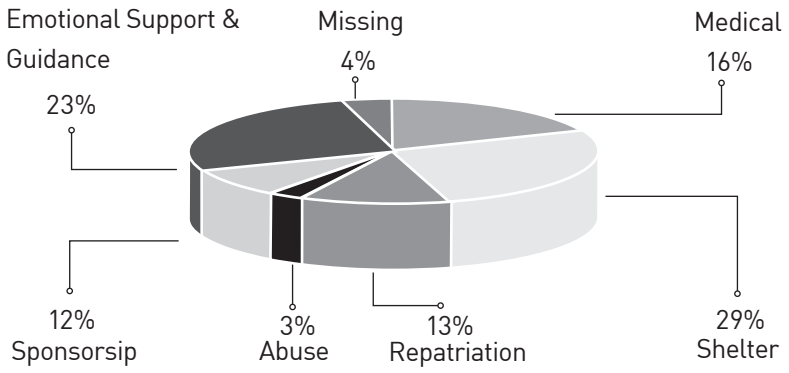


Source : ChildNet, April 2003 – March 2008

Intervention calls to CHILDLINE 1098

Calls were received requesting for assistance/support such as medical help, shelter, repatriation, rescue from abuse, emotional support & guidance, and tracing missing children.

Figure 1.2 Assistance Provided



Source*:* ChildNet, April *2003 – March 2008*

Of the total calls received, 29% of the children were provided assistance for shelter, 23% emotional support & guidance, and 16% were provided assistance for medical help. 4% of the calls were received from parents reporting their child missing and in this case CHILDLINE helped in tracing the children.

Out of 1,325 cases covering 25 states in India, 13% of the calls were recorded from Maharashtra.

This exploratory study is an attempt by CHILDLINE India Foundation (CIF) to gain understanding on basic aspects of mental retardation ranging from understanding people's knowledge level on the issue, awareness of services, the role of CHILDLINE service and expectations from the helpline service.

There was a long felt need for understanding mental retardation; skills to identify and handle mentally challenged children. This need was expressed by CHILDLINE team and staff at various meets. The study is hence very basic in nature with importance on implications for CHILDLINE.

2

OBJECTIVES AND METHODOLOGY OF THE STUDY

2.1 Area of the Study

The study on Mentally Challenged children was carried out in Sholapur, Maharashtra. Maharashtra was chosen because of proximity and limitation of time. Out of 1,325 cases received in CHILDLINE, in 25 states across India, 13% of the calls were recorded from Maharashtra. Initially it was decided to conduct a comparative study in Rural and Urban area of Maharashtra. Pune was chosen for the urban site. Following various rounds of interaction with experts in the field Sholapur was chosen as the site for rural study. However, during the explorative visit to Sholapur it was observed that the study could be carried out in Sholapur alone.

The study was done in association with Jivhala Society for the Mentally Handicapped, Sholapur, which was, set up in 1979, and works for the education and rehabilitation of Mentally Retarded children. The society runs two day schools (for children below 18 years) and one residential farming workshop (for adults above 18 years).

The scope of the study was defined to cover some basic aspects of mentally challenged children and their families, in order to observe co-relation of the awareness and practices of Child Protection to various parameters. Specific aspects related to Rights of such children were also explored.

Scope of the study included:

- Pre-birth care of the mother and child.
- Attitudes and perceptions about Mentally Retarded children.
- Education related issues such adjustment as in the school, progress, improvement after joining the school, improvement in the education system etc.
- Knowledge and awareness of mental retardation.
- Awareness of services for mentally challenged and the accessibility to these services.
- Awareness of the Rights of the child.
- Knowledge of and participation in Parent Teacher meet and other support groups.

2.2 Methodology

The study was organized in Sholapur district of Maharashtra. It was done at three levels – District, Taluka and Village. At the District level the study was carried out in Sholapur, and at the Taluka level in Barshi. It was initially decided to carry out the study at the District and Taluka Level, but during the course of the field visit it was found that there were children in the neighbouring villages who were not going to any school. Based on the field visit and information gathered from the local people the study was carried out in nine nearby villages also. Provided below is the list of names of District, Talukas and Villages where the study was conducted.

Table 2.1

Sl.No	Area	Sample Size
District		
1.	Sholapur	44
Taluka		
2.	Barshi	28
Villages		
1.	Kandalgaon	3
2.	Kavahe	3
3.	Lakshyachiwadi	2
4.	Shingewadi	3
5.	Nagobachiwadi	1
6.	Shirale	2
7.	Dhanure	1
8.	Karamba	4
9.	Gulvanchiwadi	2
	Total	**93**

2.3 Sampling

An exploratory study was conducted in the month of February 2007 to identify the area and sample for the study. The interview schedule was piloted during the exploratory study. The respondents for the study were parents of the Mentally Retarded children; they were chosen through Purposive Sampling[1].

The data was collected from parents and concerned personnel working in the field through detailed personal (structured) interview schedule covering both quantitative and qualitative questions. Each interview lasted an average of 30 minutes.

2.4 Method of Data Collection

A structured interview schedule consisting of both qualitative and quantitative questions was drafted for data collection. The schedule was piloted in the study area before actual data collection.

A list of children from the schools was selected and direct one to one interviews were organized with the parents. In the villages, a list of children was collected from the panchayat heads, parents of mentally challenged children and doctors. Investigators visited the homes to collect data as these children were not enrolled in the schools. In-depth interviews were conducted with the parents, teachers, principals and professionals from the field.

2.5 Data Analysis

Following the data collection, the data was categorized and coded manually. The data was then analyzed in SPSS 15.0 software.

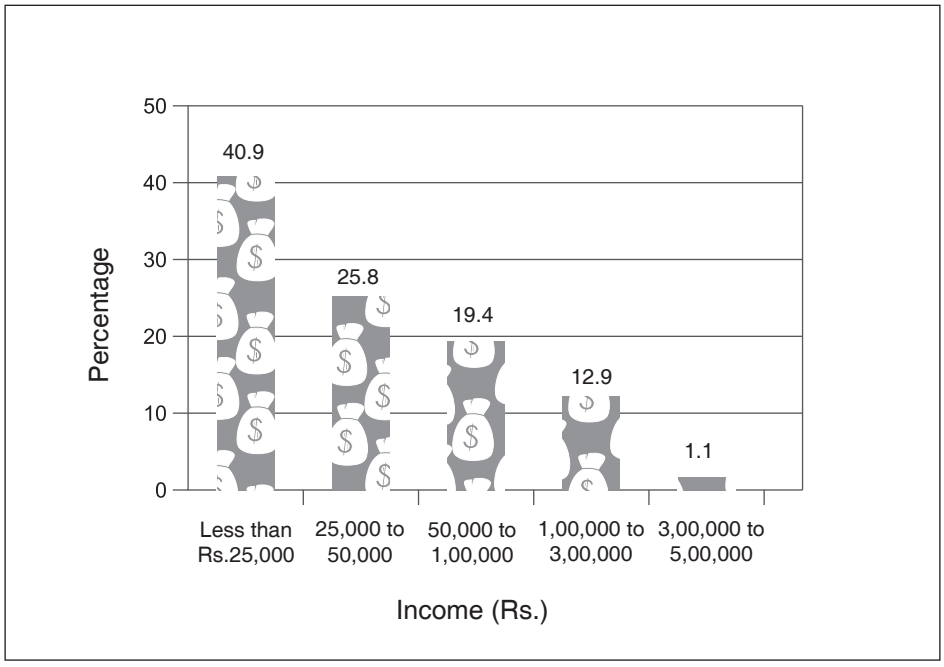
1. A purposive sample is one, which is selected by the researcher subjectively. The researcher attempts to obtain sample that appears to him/her to be representative of the population and will usually try to ensure that a range from one extreme to the other is included.

FINDINGS OF THE STUDY

3. 1 Socio-Economic Profile of Respondents

Better economic conditions means better access to services, facilities, housing and better food and nutrition. People from economically well off background can provide better for their children as they have the means and knowledge to access the services.

Figure 3.1 Annual Income



Among the respondents interviewed 41%have an annual income of less than Rs. 25,000, which is approximately 2000 rupees per month. 67% of the families are living with less than Rs. 50,000 annual income. Only 14% of the families are living with annual income of more than one lakh rupees.

Note: Due to poor economic conditions children are deprived of nutritious food, are unable to get access to better health care facilities, and are exposed to disease producing conditions and environmental hazards.

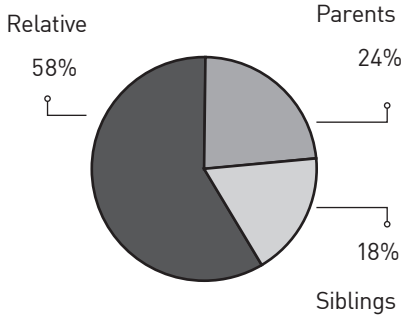
It also deprives children from accessing facilities such as cultural, recreational and day-to-day experiences, which are very essential for their holistic development. Such under-stimulations can result in irreversible damage and can serve as a cause of mental retardation. In Indian conditions this has proved to be an important causative factor.
(*Source – Effects and Usages of communication Media for the Mentally Challenged, Dr Asha Deshpande, 2005*)

3.2 Biological factors and Maternal condition

There are instances of mental retardation that are determined at conception. These are due to chromosomal abnormalities. Major mental disorders are caused due to chromosomal abnormalities as extra or missing chromosomes or loss of part of chromosomes. Example – Down's syndrome, caused due to an extra chromosome that is three chromosomes in the 21st pair instead of two.

Parents are the carriers of recessive genes, but the successive generations inherit the dominant genes of retardation and resulting in the offspring's born as mentally challenged.

Figure : 3.2 Relationship to the child



17 respondents reported history of mental retardation in the family. 58% reported that a close relative in the family (that is the child's uncle, grand parent etc) had similar condition. In 24 % of the cases one of the parents was mentally retarded and 18% had a mentally retarded sibling.

Note - Studies have shown association between family history and mental retardation. *(Source – Status of Disability in India, 2000).*

3.2.1 Maternal Conditions

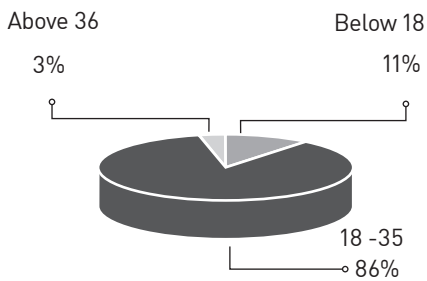
"Maternal health refers to the health of women during pregnancy, childbirth and the postpartum period. Maternal health during these stages is very important as its detrimental to the unborn child's development (physical and mental). Psychological and nutritional factors contribute to health and well being of the mother as well as the child.

Children's brain development can be affected by poor maternal iodine and folic acid status. Low birth weight in infants from malnourished mothers can cause learning disabilities and mental retardation. Iron deficiency in early childhood can affect mental development. Malnutrition leads to decreased exploratory behaviour and affects learning abilities. As per WHO Iodine deficiency is the greatest cause of preventable mental retardation and under nutrition among pregnant women in developing countries leads to 1 out of 6 infants born with low birth weight.
(Source: http://www.who.int/topics/maternal_health/en/)

This section on maternal status deal with factors such as maternal age, disease & illness during pregnancy, complications, state of mind, injury etc.

a) Maternal Age - The chances of the child being born with complications increases with increase in the mother's age. The same holds true for a girl below the age of 18 years. Studies too have shown shed light on the same.

Figure 3.3 Maternal Age at the time of conception



Majority (86%) of the mothers were in the age group of 18-35 years at the time of conception. 11% were below 18 years and 3% were above 36 years at the time of conception.

Note - Maternal Age at the time of conception is a very important factor. Studies show that the ideal age of a woman for procreation is between 18 to 35 years. Children born to mothers below the age of 18 years have more chances of being retarded as are those born beyond the maternity age of 35. There is a well-known correlation between Down syndrome and maternal age. The rate of chromosomal anomalies in mothers in the age group of 35-40 range is 1.5 percent, it increases to 3.4 percent at the age of 40 and to as much as 10 percent at the age of 45 years.

b) Maternal diseases and Infections – The period from conception till delivery is very vital for the expectant mother and needs to take care of her health. Any infection or illness during this period could have a serious impact on the unborn child. Of the total 15 respondents who reported any illness during pregnancy 59% reported illness due to infections such as jaundice, pneumonia, fever,

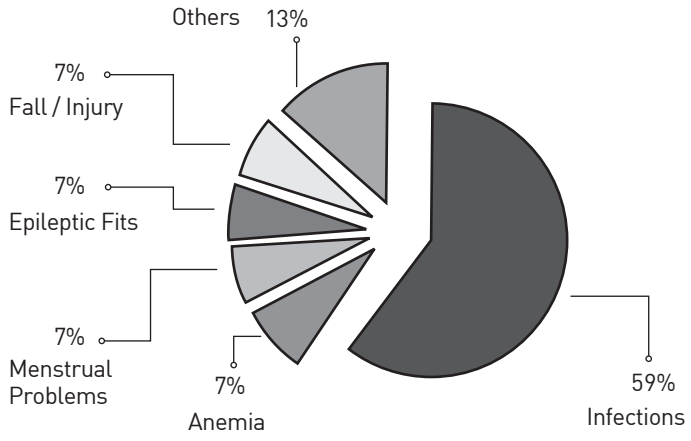
cold. The remaining 41% reported anemia, menstrual problems, epileptic fits[1], fall/injury and headache. (Refer Fig - 3.4)

While in conversation with the respondents the researcher realized that majority of the mothers from the sample group did not report any illness during pregnancy because they believed that illnesses like fevers, anemia, jaundice etc were normal occurrences and they did not see any connection between the illnesses and the child being born with mental retardation. These women and their families also did not feel the need to consult any doctor reflecting a lack of awareness regarding the possibility of complications arising due to illness during pregnancy.

Note - Diabetes mellitus, hypertension and chronic problem in kidney can damage the foetus. Hyperthyroidism in mother leads to cretinism in child and produces defects in Central Nervous System (CNS) in the growing foetus. Rubella toxoplasmosis, syphilis and cytomega, herpes, tuberculosis, chicken pox is commonly associated with mental retardation.

Injury – Injury to the abdomen of mother – injury due to falls, accidents, epileptic attacks can damage the growing foetus.
7% of the respondents had reported a fall/accident during pregnancy.

Figure : 3.4 Illness during Pregnancy

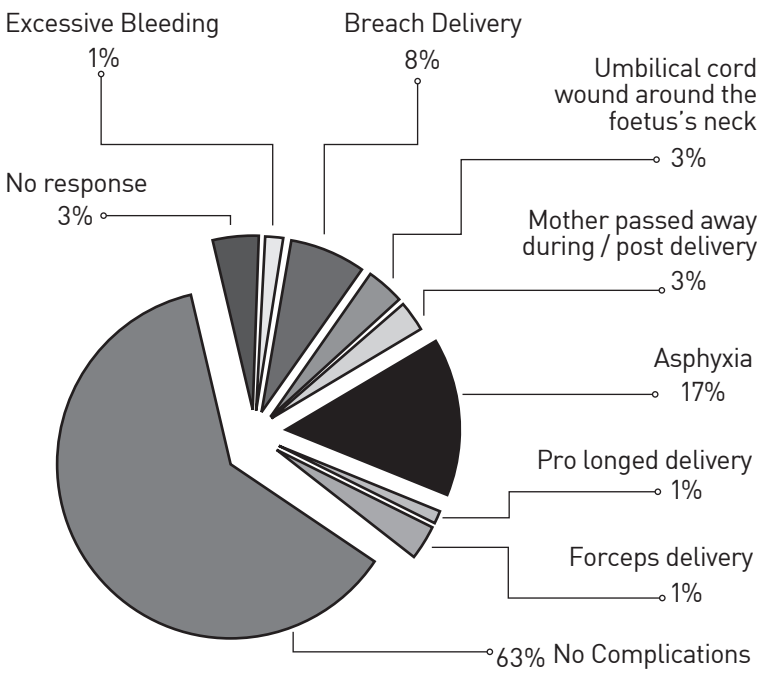


1. Epilepsy refers to recurrent small attacks associated with altered states of conscious stiffness, jerking muscular spasm; brain damage and mental retraction are the resulting effects of epilepsy.

Injury and complexities associated with injuries during pregnancy and delivery is also a contributing factor to mental retardation in children. Birth injury occurs during the first confinement and the cranial contents are subject to great internal pressure and considerable damage during delivery may lead to intracranial hemorrhage.

(*Source - A textbook of mental deficiency (subnormality), 10th edition – R.F. Tredgold & K. Soddy. London. 1963*)

Figure 3.5 Complications during pregnancy



Studying the complications during delivery 36% of the mothers reported having faced complications during pregnancy. 17% reported that their infant suffered asphyxia.[2] 8% reported breach birth. 3% of the children were born with the umbilical cord wound around the neck. This leads to suffocation due to the low oxygen supply (hypoxia); the brain gets damaged leading to mental retardation.

2. Delayed birth cry and hypoxia or Asphyxia, the child does not respirate and this desperation of oxygen (asphyxia) for more than 5 minutes or low supply of oxygen (hypoxia) can lead to brain damage. The causes of this are difficult labour (dystocia), depression of the fetal respiratory center due to excessive anesthesia and obstruction of respiratory airway.

One respondent reported prolonged delivery[3]. One respondent stated that forceps was used during delivery. Inappropriate use of forceps or negligence during delivery, attended by untrained maids, deliveries at homes cause brain damage and mental retardation in the child.

c) Deprivation - Deprivation and lack of adequate oxygen and basic nutrients can lead to mental retardation and hamper the normal growth of the foetus. Severe anemia at the time of pregnancy has been associated with mental retardation. Of the total 15 respondents who reported any illness during pregnancy, 7% reported suffering from anemia. (Refer Fig - 3.4)

d) Maternal stress – Maternal stress, tensions, worries and mental shocks to the mother, during pregnancy especially in the 1st trimester, affects the mental development of the foetus. In the study it was found that mothers were emotionally stressed during the pregnancy. The emotional stress was due to family crisis, domestic violence, economic crisis and fear.

Table – 3.1 Maternal Stress during Pregnancy

Sl. No	Maternal Stress	Frequency (%)	Total (%)
1.	Family Crisis (death in the family)	5 (29.4)	17 (100)
2.	Domestic Violence (fights, physical abuse, birth of girl child)	7 (41.2)	17 (100)
3.	Economic Crisis (unemployment, only earning member)	2 (11.8)	17 (100)
4.	Fear (abortion, complication, birth of mentally challenged child, taken medication without consultation, Emergency contraception)	4 (23.5)	17 (100)

(Multiple Options)

3. Draining of the amniotic fluid during prolonged labour can lead to brain damage, motor abnormalities, and seizures in the fetus.

17 respondents reported that during the course of their pregnancy they were under emotional stress due to various reasons. 41.2% of the respondents were under stress due to domestic violence at home. There were constant fights at home, at times physical abuse also. Birth of the girl child was also another factor for domestic violence.

29.4% reported having undergone stress due to death of a close family member at the time of pregnancy. 23.5% were under stress due to fear of loosing the child through miscarriage (1st child), birth of a mentally challenged child (previous child is mentally challenged), and medications taken without consulting the doctors that could lead to complications.

11.8% stated the reason being economic crisis in the family.

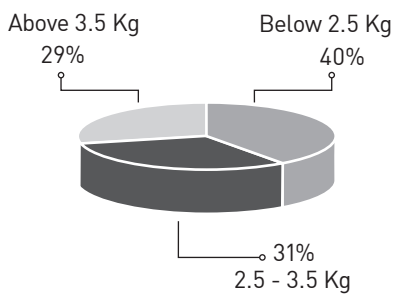
e) Premature Birth – A premature infant has been defined as either born before 38 weeks of gestation. Maternal health problems, dietary deficiency, inadequate pre natal care, cigarette smoking by the mother and extremes of maternal age are the common causes of premature births.

Three of the children from the sample group were born premature; they were born in the seventh month that is 28 weeks. The rest of the respondents claimed that they had a full term pregnancy.

f) Low birth weight - babies are found to have an I.Q. less that 80 and are found educationally handicapped. They are susceptible to the neurotoxic effects of bilrubin that can be injurious to the brain. Also premature babies are weak and prone to infections, they have low sucking capacity and cannot swallow adequate amounts of mother's milk. This affects the development of brain and may lead to mental retardation.

Out of 93 children about 40% of the children were born with low birth weight of less than 2.5 Kgs.
(Refer Fig – 3.6)

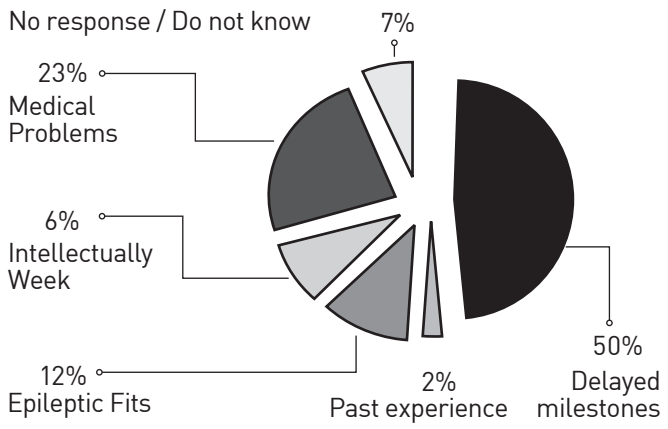
Figure 3.6 Weight of the child



3.3 Knowledge of Mental Retardation

Exploring the awareness level of the parents on the condition of their child, 50% parents reported that they realized their child is mentally challenged when the child was slow in reaching the developmental milestones such as crawling, walking, talking etc. in comparison to other children of the same age.

Figure : 3.7 Knowledge of Mental Retardation



About 35% respondents reported that their child had attacks of epileptic fits and other medical problems (such as jaundice, obesity, wound on head, weakness, did not open eyes, constant crying, sleeping long hours, showed no physical movements, hydrocephalus). It was when they consulted the doctor with these problems that they were informed that the child is mentally challenged.

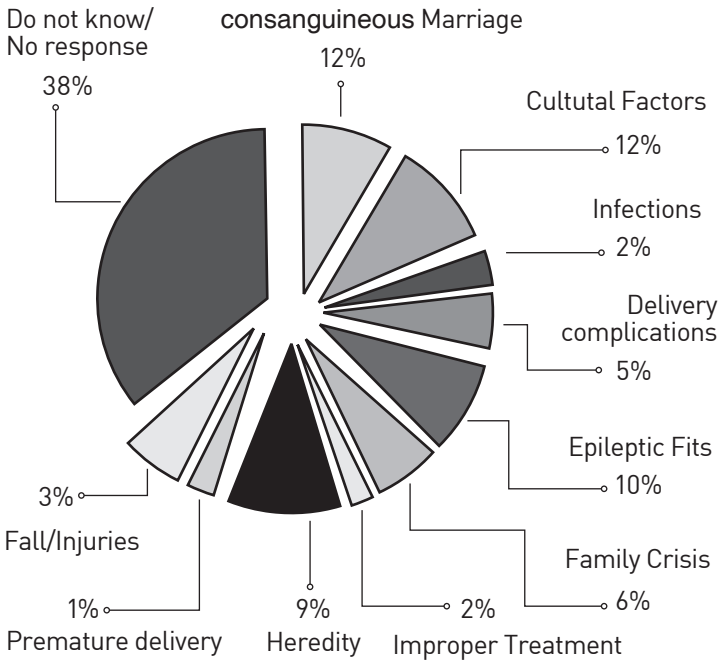
6% of the respondents realized it at the time of admission of their child into the school. At the time of admission it was brought to their notice by the teachers that the child is intellectually weak.

2% reported that they had the knowledge of mental retardation from their past experience of having a child who was mentally retarded.

a) Perceived Causative Factors

36 % of the respondents stated various factors as causative factors for mental retardation. Some of the factors mentioned by the parents were consanguineous marriages, delivery complications (umbilical cord wound around the foetus neck, intake of medications without consulting doctors, lack of oxygen, excessive bleeding, prolonged delivery, late/early pregnancy due to age), epileptic fits, heredity. Studies show that around 5% of mental retardation is caused by hereditary factors.

Figure 3.8 Perceived Causative Factors



12% stated that God, fate, past sins, watching something scary (movies), crossing a dead body (cultural factors) etc are responsible for mental retardation.

2% of the respondents reported that metal retardation is caused due to Infections (Jaundice, typhoid, fever) during pregnancy.
2% stated that wrong treatment by doctors (negligence, did not provide proper medications, delay in attending to the patient) during pregnancy was the causative factor.

Family crisis situations leading to depression, stress, tension is another set of factors that causes mental retardation according to some of the parents. Due to stressful situation in the family such as violence, pressure on the women to deliver a healthy baby in the case of earlier child born mentally retarded, financial crisis, work pressure etc also put the mother under undue emotional and physical stress. 6% of the respondents believed that family crisis results in the child being born as mentally retarded.

1% of the respondents said that premature delivery causes mental retardation in children.

As per a British Study conducted by the University of Nottingham, cerebral palsy, mental retardation, chronic lung disease, blindness and hearing loss are among the lifelong challenges that are often faced by extremely premature infants. As per the study 41% of the extremely premature group have severe or moderate mental impairment at six years of age. The results of study showed that 22 % had severe disability, such as severe cerebral palsy (children not walking), very low cognitive scores, blindness or profound deafness. (**Source** - http://health.dailynewscentral.com/content/view/268/63)

b) Source of Information of Mental Retardation

Exploring the sources from which they have gained knowledge/information on the same it was found that their responses were negligible. Their source of gaining information was found to be very limited. A large number of respondents did not indicate any source of information.

Of the total 93 respondents only a very small percentage stated that they have gained their information on the issue from doctors, school teachers, media and awareness camps.

Table – 3.2 Source of Information

Sl. No	Source of information	Frequency (%)	Total (%)
1.	Doctors	6 (6.5)	93 (100)
2.	Awareness Camps	1 (1.1)	93 (100)
3.	School teachers	4 (4.3)	93 (100)
4.	Social worker	1 (1.1)	93 (100)
5.	Media (T.V/Newspaper)	5 (5.4)	93 (100)

(Multiple Options)

6.5% claimed that they got to know about mental retardation from doctors. 5.4% stated media and 4.3% said school teachers. The two main contact points for the respondents were the doctors and the school teachers of both the special schools and the normal school.

Table – 3.3 Information from Media

Sl. No	Source of information from	Frequency (%)	Total (%)
1.	Read (books, magazines, newspapers)	12 (12.9)	93 (100)
2.	Radio	2 (2.2)	93 (100)
3.	Television	18 (19.4)	93 (100)
4.	Films	5 (5.4)	93 (100)

(Multiple Options)

Of the 93 respondents 12 (12.9%) said they had read about mental retardation in books, magazines and newspapers.

24.8% of the respondents had watched programmes on television including films on mental retardation. Programmes such as a talk show, some documentary, movies etc. and 2.2% have gained some information from radio shows.

3.4 Outlook on the child's future

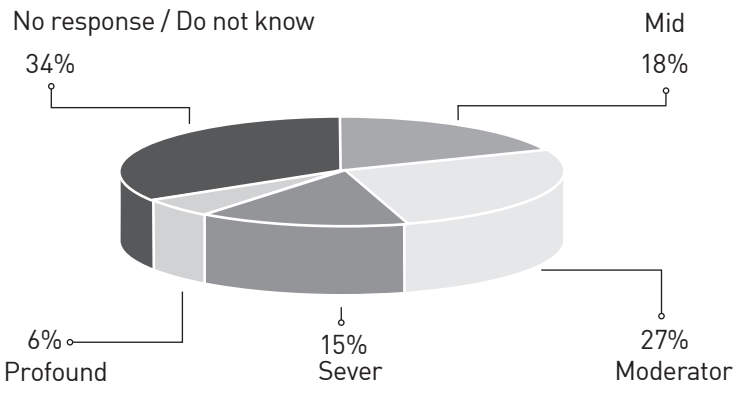
Mentally Retarded children have low IQ levels and consequently have limited abilities of functioning. Within this ability they can be trained to their optimum level and can master certain tasks. However, parents often find it difficult to accept their child's limitations and have overly high expectations of the child, thereby putting the child and themselves under a lot of strain and pressure.

The Child's Intelligent Quotient (IQ).

The study results show that 34% of respondents were not aware of the IQ level of their child. The reasons being some of them were from the interior villages and were not aware of the services available such as IQ testing, special schools etc. Another factor being most of them were illiterate and hence did not know the procedure of IQ testing, where it is done etc. And a few were not aware of their child's IQ level though the IQ testing was done.

27% of the children fell in the category of moderate mental retardation, 18% Mild, 15% severe and 6% profound mental retardation.

Figure 3.9 IQ of the Children



Improvement in Child's Condition

Exploring further their knowledge of mental retardation, the respondnets were asked whether they think their child's condition can be improved? As per the child's IQ, the child's condition can be imroved/make progress to a certain level only and not beyond that. However majority of the respondents(60), believe that the child's condition can be improved.

Table – 3.4 Improvement in Child's Condition

Sl. No	Extent to which the child's condition can be improved	Frequency (%)	Total (%)
1.	Made self reliant	28 (46.7)	60 (100)
2.	Engage in economic activity	6 (10)	60 (100)
3.	Improved interaction	4 (6.7)	60 (100)
4.	Attend school	2 (2.3)	60 (100)
5.	Do household work	6 (10)	60 (100)
6.	Hope of improvement (overall)	15 (25)	60 (100)

46.7% believe that the child's condition can be improved to the extent that he/she will be self reliant, that is the child will be independent, and will be able to do his/her own work.

25% believed that the child would improve post marriage or in a span of few years. 10% expected the child to be able to do household chores and engage in economic activity respectively. While mentioning economic activity, parents expected their child to engage in small jobs or business as in setting up and managing a shop This is irrespective of their degree of retardation. This expectation is more indicative of their optiistic aspirations and often has little to do with the reality of the situation.

6.7% expected the child to be able to recognize family members and relatives. And 2.3% expected the child to be able to attend school and vocational training course by self.

3.5 Present status of the child

Majority of the children were self sufficient and were able to perform basic functions without assistance. Maroity had to say that the child's condition had improved after joining school.

48 (73.8%) reported that the child's condition had improved after joining the school. And 13 (20%) stated that there was no change in the child's condition even after joining school. On the whole the children were capable of self-care such as bathing, brushing, dressing, feeding etc

Table – 3.5 Ability of the child in self-care

Sl. No	Ability of self care	Frequency (%)	Total (100)
1.	Feed self	66 (71)	93 (100)
2.	Wash hands	58 (62.4)	93 (100)
3.	Toilet train	50 (53.8)	93 (100)
4.	Brush teeth	49 (52.7)	93 (100)
5.	Dress self	37 (39.8)	93 (100)
6.	Comb hair	36 (38.7)	93 (100)

3.6 Awareness of services

The section on awareness of services dealt with knowledge of schools (special schools) in their area, financial provisions/schemes, legal provisions, and helpline services for children.

Figure 3.10 Awareness of Special Schools in the Locality

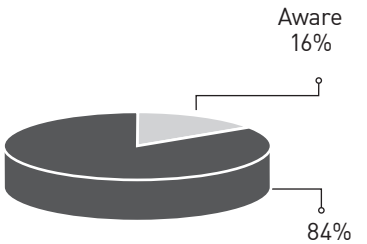


Figure 3.10 Awareness on Financial Provisins & Schemes

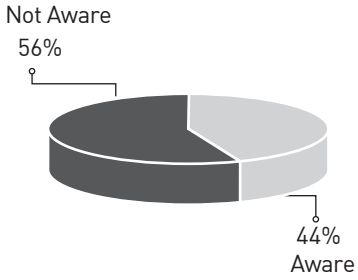


Figure 3.10 Awareness of any Legal Provisions

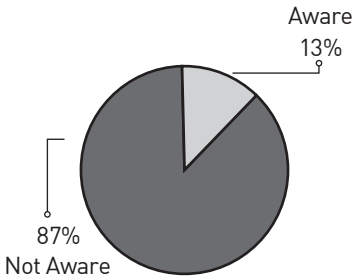
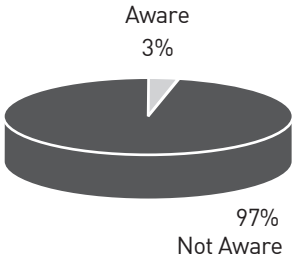


Figure 3.10 Awareness on Helpline service for children

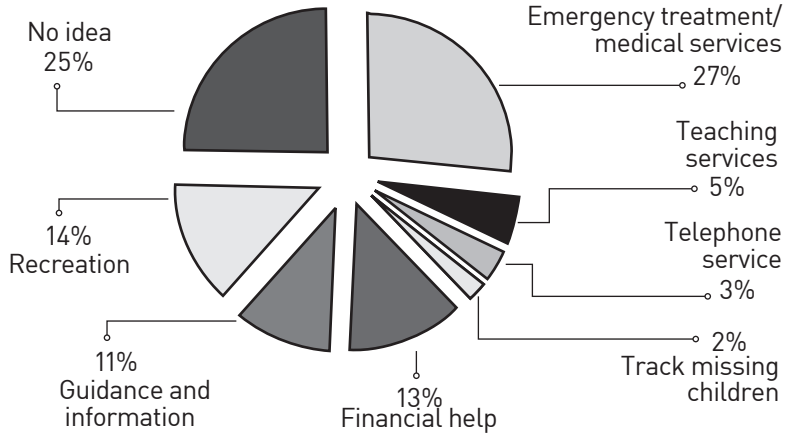


Only 16% were aware of other residential and special school in their locality. 44% were aware of the financial (government) provisions available for the mentally challenged children. Respondents shared that they were aware of the scholarship scheme as the children were receiving money through the school. They were aware of travel concessions and pension schemes. Only 13% knew of legal provisions available for the children. Of the total respondents, only 23.7% of the respondents had availed any provisions and services available for the children.

3.6.1 Awareness of helpline service

Only 3% of the respondents had heard of any helpline services for the children. Of the total respondents only 3 were aware of CHILDILNE service and that it's a telephonic helpline service for children. When the respondent was given a brief on the CHILDLINE service and asked whether they would like to have such a service. They responded positively stating that yes they would like to have helpline service for children.

Figure 3.11 Expected Services from the Helpline



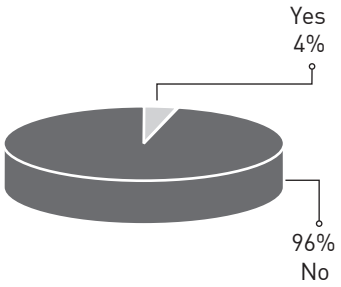
27% of the respondents wanted a service that would provide emergency service to them, that is whenever their child falls ill (epileptic attacks) the helpline should be able to provide immediate service. 13% person wanted financial assistance to be provided by the helpline as many parents said they find it difficult to bear the medical expense of the child. 14% wanted the helpline to provide recreational facilities for the children. 11% indicated that they would like the helpline service to provide them more information and guidance regarding mental retardation and the various services and facilities available. 2% stated that they would like the helpline to help trace-missing children as many a time the child tends to loiter around when let out to play with other children and not return home. 5% wanted teaching assistance from the service, as in some one to come home and teach the child.

3.7 Mentally Challenged Children and Rights

Every child and young person (i.e. any one under the age of 18 years) has rights and responsibilities. India is a signatory of the United Nations Convention on the Rights of the Child (UNCRC) and has agreed to abide by the same. We are legally bound to implement and ensure that the rights of the child are protected.

*Article 2 (1) of UNCRC states that the **State should respect and ensure the rights set forth in the present Convention to each child within their Jurisdiction without discrimination of any kind**, irrespective of the child's or his or her parents or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, **disability**, birth or other status.*

Figure 3.12 Awareness of Rights of the Child



Article 23 further provides guidance on realizing the rights of the child, specifically the disabled child (mental & physical).

However in a country with population 440 million children, the plight of the disabled child is pitiable. And that of the mentally challenged child is further distressing. Our findings show that only 4.3% of the respondents were vaguely aware about the rights of the child.

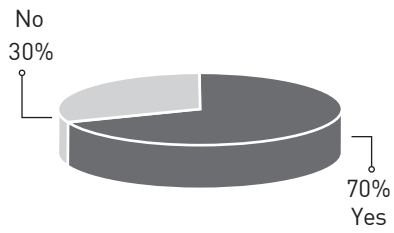
3.8 Education

The Ministry of Social Justice and Empowerment (MSJ&E), the nodal ministry for disabled people initiated a number of special education programmes for people with disabilities. These were implemented by the NGO sectors with grant-in-aid provided by the MSJ&E for starting both residential and non-residential school. Special schools for specific category of disability were created. The schools catered to the needs of the children with visual impairments, speech/hearing impairments and those who are intellectually challenged.

Children with mental and behavioral problems are given education/skill development facilities in the institutions meant for them. They have not been integrated into mainstream schools. *(Source - Training and Empowerment of People with Disabilities: India 2002. S.K. Rungta)*

This section on education sheds light on various aspects related to education of the child, whether the child attends special school, has the child always attended a special school or a normal school along with other children in the society, child's adjustment and progress in the school, and whether the child is happy attending the school.

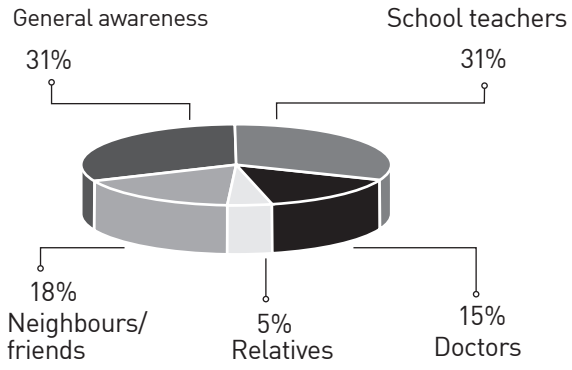
Figure 3.13 Child attends school



70% of the children attended special school. The remaining 30% did not go to school or had discontinued their schooling. The reason being the child constantly falling ill (epileptic attacks), school too far from the house.

None of the respondents reported any kind of trouble during admission. Majority (31%) of the parents got to know of the special school in their areas from school teachers and general awareness.

Figure 3.14 Source of Knowledge of Special School



Teachers from the special schools conduct periodic survey of specific blocks. The purpose is to get a head count of total number of children in the area and their status. It was the teachers who provided knowledge of the school and its services and the need for the child to attend the school. Also school teachers from normal schools were source of information.

31% respondents were aware of the special school and its services. 18% stated that they got to know of the special school from their neighbours and friends. Many of whom had children who were mentally challenged and encouraged the respondents to enroll their children into these schools (Ref fig 3.14).

15% were told about the special schools by the doctors. And 5% got to know of the special school from their relatives.

44% of children had been enrolled into other (normal) schools before being enrolled in the present special school. Either the parents were not aware of the mentally challenged condition of their child or were aware but not willing to accept that their child needs to go to a special school (Ref fig 3.15).

Figure 3.15 Child attended other school before the present

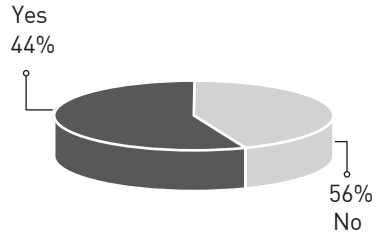
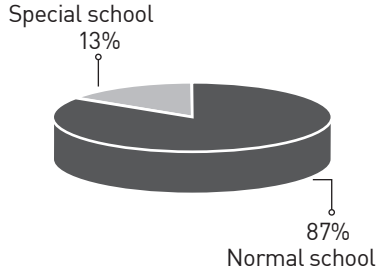


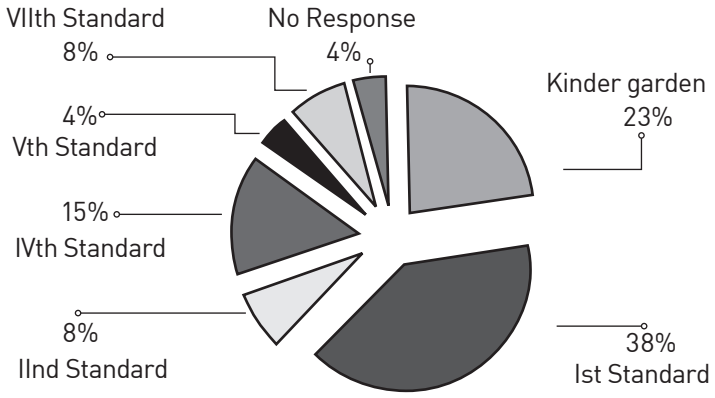
Figure 3.16 Nature of school



Of the 30 children, 26 (87%) had attended school for normal children. And 4 (13 %) had attended special school, which included special school for the deaf and dumb also (Ref fig 3.16).

38% of the children had attended up to standard I in the normal school. 15% attended classes upto IV standard and 8% had studied up to Standard VII. Parents were not aware that their child was mentally challenged until they noticed that their child never went beyond a particular class. Also it was the teachers who noticed and brought to the notice of the parents that the child was not eligible for a regular school (Ref fig 3.17).

Figure 3.17 Standard upto which the child studied in the Normal school



According to the parents 83% of the children were happy in the school and are well adjusted. 83% got along well with the teachers and the other students. They mingled and interacted with others and had no problems. However, 15% reported that their children were not happy with the school and had problems with other children and teacher. The child would fight and not socialize with others.

Figure 3.18 Is the child happy in the Special school?

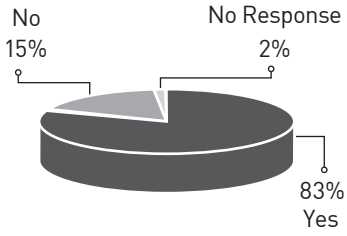
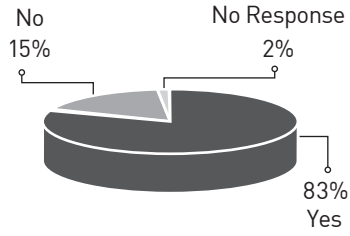


Figure 3.19 Child gets along with teachers & other children



3.9 Parents Interaction with the Teachers

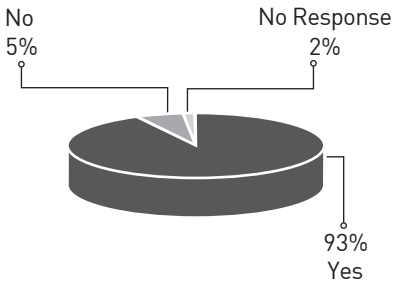
It is very essential that the parents take a keen interest on their child's progress and achievements in the school. This helps the parent to not only know how well their child is fairing in the school but also what are the problems faced by

the child. For the child too it is encouraging to know that their parent is taking interest in what they are doing and this works as a motivational factor for them.

This section looks at the parent's involvement in the child's progress, interaction with the school staff, view of the school (curriculum/teaching) and the changes they would like and the changes they have observed in their child post joining the school.

93% reported that they regularly visit and meet the teachers. 5 % of the parents stated that they do not go to meet the teachers and reasons cited were:

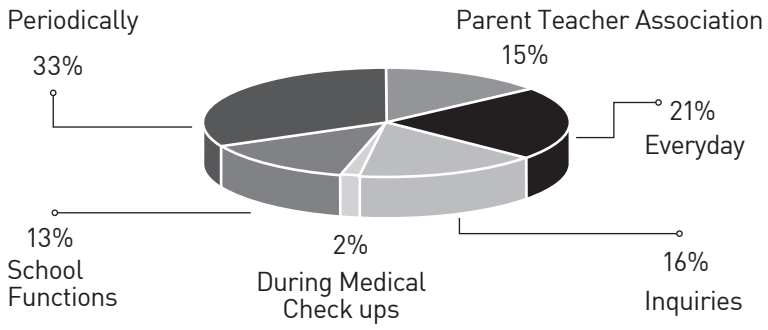
Figure 3.20 Do you go to meet the teachers?



- Found no progress/improvement in the child post joining the school. Hence no point in meeting the teachers. Some of the parents felt that their children had shown no progress since joining the school. They said that the child has not learnt to read the letter of the alphabet and could not retain anything that was taught at school. The parents took this as a failure on the part of the school and hence said they saw no reason in meeting the teacher.

- Due to the child's behaviour. The child begins to cry every time he/she sees their parenst in the school. The child gets very upset whenever the parent went to the school and would start to cry.

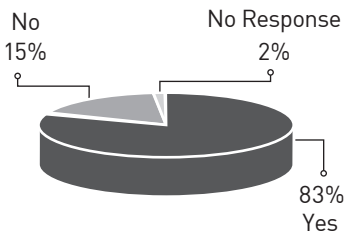
Figure 3.21 Frequency of meeting with teacher



Parents were in close touch with teachers in the school. Most of them met on a very regular basis ranging from every day to periodically and during school functions and Parent Teacher Meet. During these meets they usually discussed about their child and his her progress in the school. Majority (33%) of the parents met the teachers periodically (ranging from once in 15 days to once in 2-3 months).

21% met the teachers when they went to drop and pick up their child at the school. 16% visited the school to inquire about scholarship, if called by teacher, or whenever the child did not go to school. 15% of the parents met the teachers during the Parent Teacher Meet (Ref fig 3.21).

Figure 3.22 Happy with the School



13% met the teachers' during the school functions such as Annual Day/ Sports Day, which is an Annual Event. A very small percent (2%) visited the school during medical check-ups, which is again an annual event.

83% of the parents were happy with the school, the teaching methodology and the care provided to their children. 15% reported that they were not happy with the school.

40% of the parents were not happy with the school as they did not find any improvement in child. The child has not learnt how to write, and also does not remember what ever is taught or told to the child. 30% of the respondents did not provide any response on why they are not happy with the school. 20% said that they were not happy with teaching. 10% said were dissatisfied as there was no special teaching (follow-up is not done) given to the children.

Figure 3.23 Reasons for not being happy with the school?

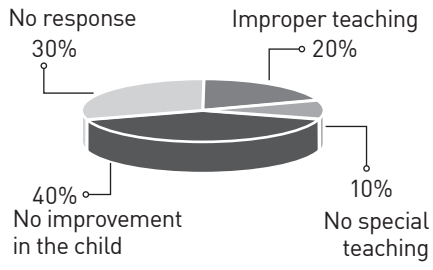
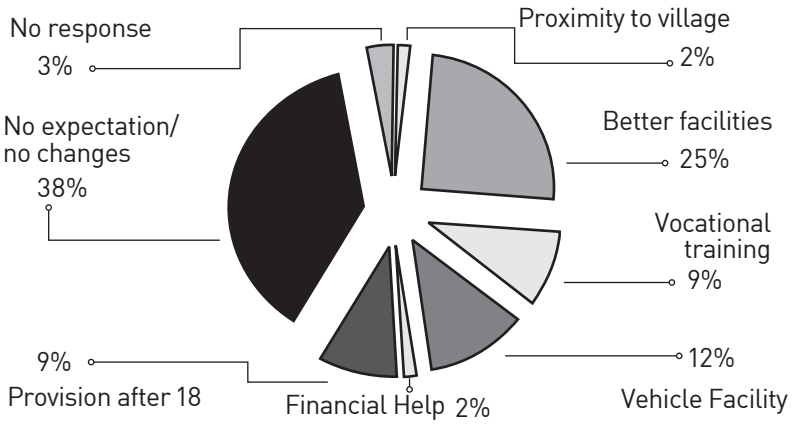


Figure 3.24 Suggested Changes



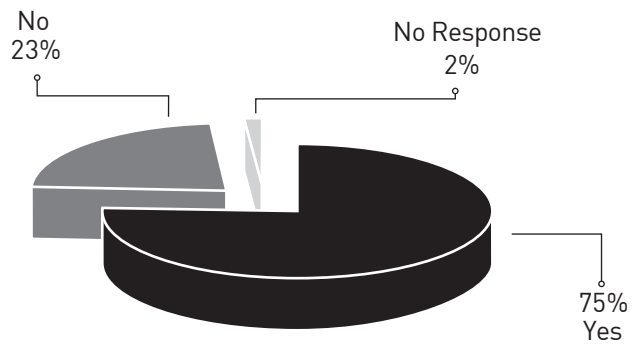
When asked if they would like any changes in the school, 38% had no expectations and did not suggest any changes. 25% suggested they would like better facilities in the school such as specialized teachers, a more interesting and interactive mode of teaching, and they would like the school to provide hearing aids free of costs to those who need them 12% wanted vehicle facility. This was suggested by those whose houses were far away from the school. They wanted a school bus or auto rickshaw to be introduced by the school.

Another reason for suggesting this is the girl child. When the house is far away from the school, the children (girls) have to travel a long distance and often face eve teasing and harassment by people on the way. Due to this some of them were irregular in attending school. Also it is not possible for parents to take their child to school daily as they are daily wage earners. And if they miss their work it means not getting paid for the day, which they cannot afford.

9% wanted vocational training and provisions for children above the age of 18. In vocational training children were taught to make lamps, candles etc. Parents suggested that music also be included in vocational training.

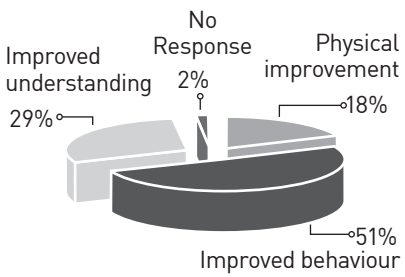
Many parents were concerned about their children once they crossed the age of 18 years as the school is only for children below 18 years of age. They were not aware of facilities for children above 18. One parent expressed the need for financial help for bearing the child's medical expense.

Figure 3.25 Improvement in the child post joining the school



49 (75%) respondents said that their child had improved after joining school. 23% said they found no improvement in their child after joing the school.

Figure 3.26 Changes observed in the child



51% of the children showed improved behaviour. Children were able to dress and brush their needs by themselves without any assistance. Although a number of children need assistance in taking care of their bodily needs, they were toilet trained. They were disciplined, did not use bad words, did not scream and cry needlessly, All the children willingly attended school. 29% of the parents felt that the child's understanding of general situations had improved. They were able to buy things from shops, switch on the television, and study at some level. 18% responded that the child showed improved physical movements. The child is able to walk, do yoga, eats well (hand –movement coordination).

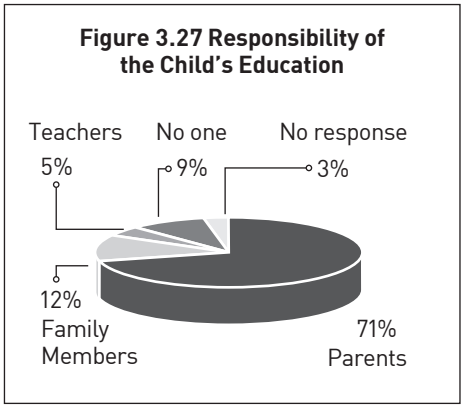


Figure 3.27 Responsibility of the Child's Education

Most of the time the responsibility of child's progress in school and education was taken up by the parent, as reported by 71% of the parents. 12 % reported that family members also shared the child's responsibility. For 3 (5%) it was teachers who took the prime responsibility regarding the child's progress and performance in the school.

3.10 Acceptance of the child

Every parent expects and wishes for a normal child. And in a country like India, the desire for a male child is still very strong in many parts of the country. With this existing mindset, the acceptance of the fact that the child born is mentally retarded is very stressful for the parents. The knowledge of the child being mentally retarded often brings about a gamut of emotions ranging from denial, guilt (why me?), anger, sorrow and finally reluctant acceptance. And often in all these, the parents continue to hope for the best or a miracle. that the child will one day be normal.

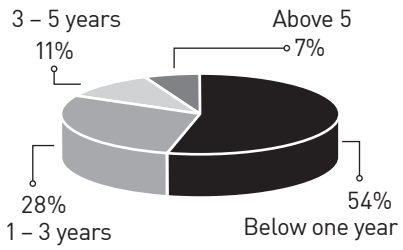
Table – 3.6 Reaction of the parent towards the child

Sl. No	First reaction on knowing the child is mentally challenged	Frequency (%)	Total (%)
1.	Denial	3 (3.2)	93 (100)
2.	Anger	4 (4.3)	93 (100)
3.	Shock	10 (10.8)	93 (100)
4.	Sorrow	79 (84.9)	93 (100)
5.	Any other	7 (7.5)	93 (100)

(Multiple Option)

Majority (84.9%) of the respondents experienced only sorrow when they realized that the child is mentally challenged. 10.8% were shocked to know that the child is mentally challenged. 4 (4.3%) respondents expressed anger after having got to know that the child is mentally challenged. And 3 (3.2%) had gone into denial. They refused to acknowledge that the child is mentally challenged (Ref table 3.6)

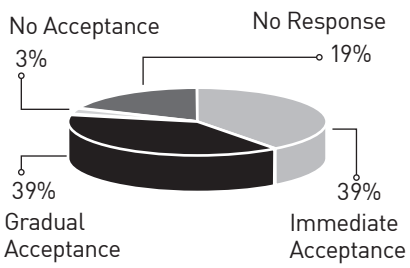
Figure 3.28 Age at which found the child is Mentally Challenged



82% of the parents realized that their child was mentally challenged by the time the child was three years old. Of which 54% realized that their child was not normal by the time the child turned one year old. 11% realized that their child was mentally challenged between the age of three and five and 7% realized it only after the child had turned five.

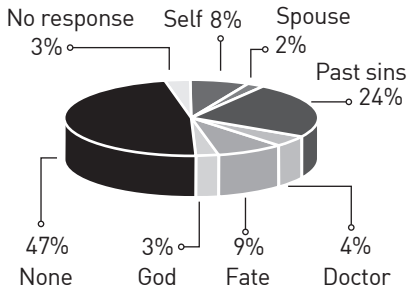
Taking into consideration the expectation of parents, they undergo a whole range of emotions. And often it becomes extremely difficult for the parents to accept that their child is mentally challenged.

Figure 3.29 Time taken to accept the child



39% accepted the child immediately. They did not have any problem once they realized that the child is mentally challenged. They did not consider the child to be a burden or a hindrance in any manner. Another 39% took time to accept the child. Their gradual acceptance of the child varied from one to five years of time period. 3.2% indicated that they have not yet accepted the child to be mentally challenged. They refuse to accept the fact. 19% did not provide appropritae response.

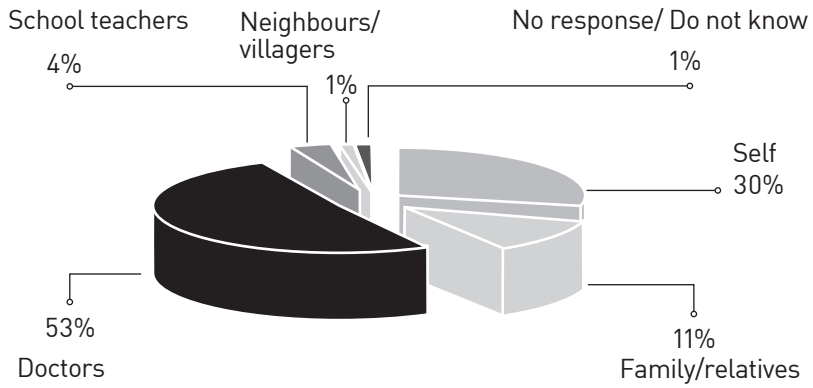
Figure 3.30 Whom do you hold responsible for the child's condition?



47% did not hold anyone responsible for the child's mental retardation. 24% believed past sins (wrong deeds committed in the previous birth) to be responsible for the child to be born mentally challenged. 9% believed that their fate was responsible. And 8% expressed that they hold themselves responsible for the child's mental retardation. 4% respondents held the doctors responsible. According to 3 (3%) respondents God was responsible. And the remaining 2 (2%) stated that their spouse was responsible for the child being born mentally challenged.

In the discussion on how they got to know of their child's state a little over half (53%) the respondents said they got to know that their child is mentally challenged from the doctors. 30% came to know that the child is mentally challenged by themselves. They were already aware of mental retardation and hence could know that their child was mentally challenged. 11% were told that the child is mentally challenged by their family members and relatives. And 4% got to know of the status of their child from the school teachers. 1% of the respondents got to know that the child is mentally challenged from neighbours and villagers.

Figure 3.31 Who brought to notice the child's state?



3.11 Attitudes and Perceptions towards the Child

Social stigma is still attached to disability. People often tend to look down upon a disabled person or for that matter any thing that is not normal. As a result of which the normal socialisation of the person and the family is greatly affected, both within the family and in the society at large.

Figure 3.32 Are the siblings sympathetic towards the child?

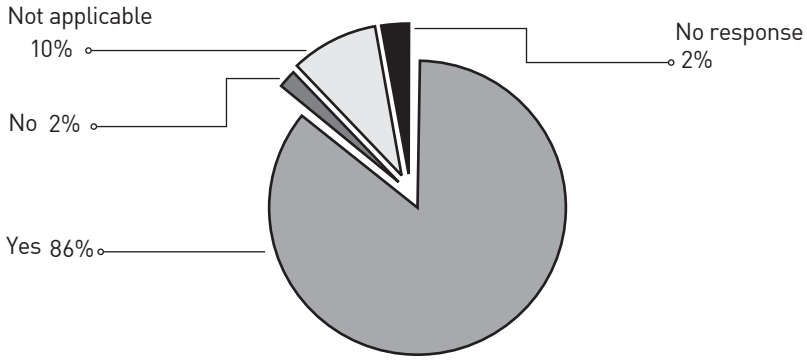
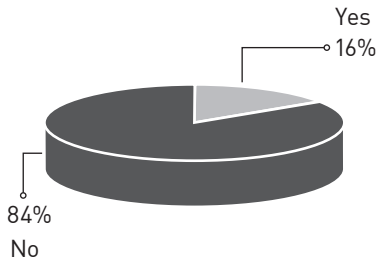


Figure 3.33 Feel inferior due to your son/daughter

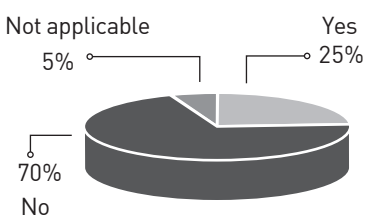


When finding out about the attitude of Siblings towards the mentally challenged child, 86% reported that their other children were very sympathetic towards the child.

In 9 (10%) of the cases this was not relevant as the child was an only child and had no siblings. 2% respondents reported that their other children were not considerate and sympathetic towards the child. And the other 2% did not provide any specific response to the same (Ref fig 3.32). Children with disability are often ridiculed. Parents and siblings therefore often feel hesitant to take them out to social functions and family gatherings. Majority (84%) admitted that they do not feel inferior due to the status of their child. 15 (16%) mentioned that they do feel inferior or were embarrassed by their child in public (Ref fig 3.33).

65 respondenst (70%) did not consider their child to be a hindrance when seeking marriage alliances for their other children. 23 respondents (25%) felt that their handicapped child would negatively effect the chances of their siblings in conducting a good marriage.

Figure 3.34 Child hinderance to other child's marriage



The reasons citied for the child being seen as a hindrance was the negative social stigma to the family and:

- 10 (43.5%) stated that people would start questioning and believe that other child would also be the same; and that children born to siblings of mentally challenged persons would also be mentally challenged.

- 2 (8.7%) expressed that when people notice that the child is mentally challenged in the family they will point, enquire and talk about the child.

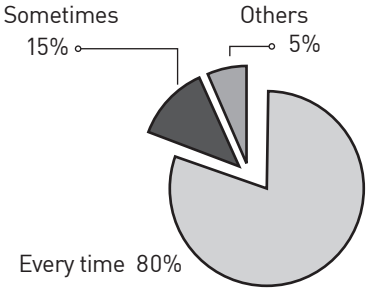
- 11 (47.8%) could not provide any particular reason for why they consider the child to be a hindrance. Though they definitely believe that the child can prove to be problematic.

3.12 Family and social interaction

The best environment for a child is his family. A healthy happy family can provide the child with the right environemnt for holistic development. Every child has a right to a family life. It is essential that the children are exposed to social and family interactions and are provided opportunity for socialising and not be segregated due to his/her disability

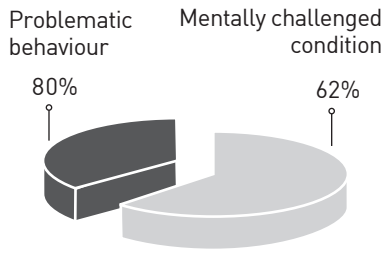
85 (91.4%) took the child along with them for social gathering as in weddings, village functions/festivals etc. Only 8 (8.6%) did not take the child anywhere. 15% took the child only for functions in hometowns and or their own village programmes. They were selective in taking their child to

Figure 3.35 Frequency of taking the child to gatherings



functions. 5% reported that they took the child to gatherings only occasionaly. This depended up on the child, if he/she was interested and the child's condition. Incase of children who showed violent behaviour or epileptic attacks they preferred not to take the child so frequently (Ref fig 3.35).

Figure 3.36 Child not taken to gatherings



Of the eight respondents who did not take the child to any gahterings, 5 (62%) said that they did not take the child because of the mentally challenged condition of the child. Parents said that the child's inability to sit in one place for even short durations, obesity – which they feared would increase the taunts directed at the child etc were some of the factors contributing to their hesitancy in taking the child out for public functions. The remaining 3 (38%) did not take the child because of the child's problematic beviour such as throwing stones, troubling others and embarrassing habits like the child asking people for money.

92% were happy to introduce their child at social gatherings and had no problems while only 8% mentioned that they did not bother to introduce their child at social gatherings (Ref fig 3.37).

Figure 3.37 Introduce Child at Gatherings

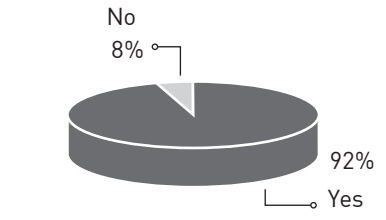
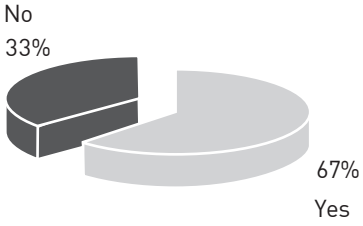


Figure 3.38 Allow to interact and play with other children



67% respondents allowed their child to interact and play with other children and did not object to this. They were happy to let their child socialize. As a result of allowing the child to socialize, parents found that this had benefited the child (Ref fig 3.38).

Table – 3.7 Benefits of interaction and play on the child

Sl. No	Benefits of interaction and play	Frequency (%)	Total (%)
1.	Improved behaviour	19 (30.6)	62 (100)
2.	Learning improved	13 (21.0)	62 (100)
3.	Learnt to play	17 (27.4)	62 (100)
4.	No response	1 (1.6)	62 (100)

(Multiple Option)

19 (30.6%) found that their child's behaviour had improved after interacting with other children. The child had begun to do work at home, behaved better, and showed greater understanding of situations and greater recognition of people than before.

17 (27.4%) stated that the child has learned to play new games and can join the group of other children. Where as earlier the child used to sit aloof, now the child is able to participate and this has boosted the child's levels of contentment and adjustment. As a result of interaction with other children 13 (21%) had found that their child's learning ability had improved in terms of improved sign language, greater ability to communicate, pronunciations of words improved. Some children had even begun to sing, 31 (33.3%) however did not let the child play and interact with other children.

Table – 3.8 Reason why the child is not allowed to interact and play

Sl. No	If not allowed to interact and play, Why	Frequency (%)	Total (%)
1.	Troubled by others	6 (19.4)	31 (100.0)
2.	Fear of road accidents	3 (9.7)	31 (100.0)
3.	Fear of animals	1 (3.2)	31 (100.0)
4.	Mentally challenged	9 (29.0)	31 (100.0)
5.	No control over bowl and bladder movement	1 (3.2)	31 (100.0)
6.	No kids in neighbourhood	2 (6.5)	31 (100.0)
7.	Aggressive behaviour	3 (9.7)	31 (100.0)
8.	Introvert	1 (3.2)	31 (100.0)
9.	No response	5 (16.1)	31 (100.0)

(Multiple Option)

A wide range of reasons were citied for not allowing the child to play and interact with other children. Majority (29%) said that they do not allow the child to play because of the child's condition, i.e., mentally challenged. As a result of which the child is not able to walk/ see, and interact on the same level with others. 6 (19.4%) stated that because of the child's condition, the child gets teased by others. Also the child does not allow the others to play, beats them and complains against them. To avoid all these they prefer not to allow the child out.

9.7% refused to allow their child to interact and play due to fear of accidents and aggressive behaviour of the child. When allowed to play the child tends to go away and near to the road, which is dangerous. Also the child's aggressive behavior is another reason for not allowing the child to play. The child tends to get into fights with other and beats them. 3.2% expressed fear of animals, no control over bowel and bladder movements and that the child is very often withdrawn in nature. 6.5% stated that there are no children in the neighbourhood, and hence the child is not allowed to play and interact. 16.1% provided no response as to why they do not allow the child to interact and play.

3.13 Parent's involvement with the child

Its essential that parent make time for their children and spend quality time with them. This could be in the form of talking to them, taking them out, spend time playing, etc. This is crucial for healthy nurturing and facilitates healthy growth and development in the child. 57% of the parents spent time with their child after school hours. 16.1% indicated that they did not spend any specific time with their child. The question was not valid for 26.9% as the child was not going to school due to reasons such as child has discontinued education, or is in a residential school.

Table – 3.9 Parents spend time with children

Sl. No	Spending time with children	Frequency (%)	Total (%)
1.	Help with studies	28 (52.8)	53 (100)
2.	Entertain the child	20 (37.7)	53 (100)
3.	Provide basic care	9 (17.0)	53 (100)
4.	Communication	5 (9.4)	53 (100)
5.	No response	3 (5.7)	53 (100)

(Multiple Option)

Among the 53 respondents who spent time with the child, 52.8% spent time with the child helping him/her with her studies and school activities. 37.7% spent quality time with the child doing activities with the child such as watching television, taking the child out on walks, playing with child etc. 17% respondents' way of spending time with the child was restricted to looking into the child's basic needs such as cleaning and feeding the child. 9.4% spent time communicating with the child, specially encourage child to speak, involve in house work etc. And a very small percentage (5.7%) mentioned that they did spend time with the child but, did not provide any specifications on how they spent the time with the child. 91 (97.8%) reported that they received help from their parents and family members in sharing the responsibility of the child.

3.14 Participation in Parent Teacher Meets/Support Group Meet

Parents teachers meet are organized in majority of the schools to discuss issues such as the child's progress in the school, behavioral problem of children, the developmental mile stones of the children, what is to be expected from the child and what the child is not capable of etc. It's basically sessions to create awareness about related issues of MR and the PTA meets also inform the parents about the various programmes for the children. 56 (86.2%) reported that they do have Parent Teacher Meets in the school. 7 (10.8%) stated that there were no meets in the school and 2 (3.1%) provided no response.

Only 4 (4.3%) were part of any support groups apart from the Parents teachers meet. The support group they mentioned was the School Improvement Committee. Of the total respondents (4) who attended the support group meet 2 reported that they met once a month and the other 2 mentioned they met annually (2-3 times). The issues the group discussed during the meet was problems of the mentally challenged children, better facilities in the school and the school curriculum.

3.15 Qualitative findings

During the course of this study, a rapport was established with the parents of mentally challenged children and the concerned heads of nearby institutes (residential and non-residential) for mentally challenged children. The interaction has shed light on various areas that need be looked into.

Concerns shared by teachers

Government Schemes/Provisions

- Government schemes and provisions neither sufficient nor easily accessible.
- Concerned departments not aware of the schemes and provision, hence the implementation is not done appropriately.
- State road transport and Railways have concession for the disabled but are not aware of the same and hence difficulties in availing these facilities.
- Grants not received on time and inadequate.
- Incase of the residential institutes, the money allotted for medical expense of the children is not sufficient.

Education

- Frustration among the teachers due to low salary.
- In rural areas teachers have to go and get the children to schools. Motivation level low in the parents and hence not keen on their child's education.

Concerns shared by parents

- Mentally challenged children especially the girl child is most vulnerable to abuse. Parents refuse to send their girl child to school fearing safety of the child. Parents with girl child (especially adolescent) face lot of problems in terms of security of the child.
- Parents are concerned as to who would take care of the child after their demise. They are not sure if the siblings and their spouse would do so in future. No financial and social security.
- Not aware of the schemes/services/acts.

4

CONCLUSIONS AND RECOMMENDATIONS

4.1 Child Protection and Mentally Challenged Children

CHILDLINE – 1098 reaches out to children in distress and in need of care and protection. Over the past eleven years of its services, it was realized that though the service reaches out to children across 82 cities/districts, there is still a large number of children whom CHILDLINE has not been able to reach out to. Broadly speaking these children are thought to be living in the 'at risk' category.

India has 420 million children, more than any other country in the world. These are children who are particularly disadvantaged because of their social, economic, physical or mental condition. These children are placed under the category of children under special or difficult circumstances. The following groups of children have been included in this category by the Government of India:

Children in labour, Street children, Children who are neglected or treated as juvenile offenders, Children who are physically or mentally challenged, Destitute children in need of adoption, Drug addicts, Children in prostitution, Children of prostitutes, Children of prisoners, Refugee children, Slum and migrant children.

CHILDLINE India Foundation (CIF) is now focusing its efforts on including children who live in the 'at risk' group in their outreach efforts. To better understand the condition and needs of these children, CIF further classified this group of children into 4 sub categories viz Children working in Mines, Refugee Children, Drug abuse and Mentally Challenged Children. This study is on Mentally Challenged children in Sholapur District.

CHILDLINE has handled numerous cases of mentally challenged children. Service provided included arranging for shelter, medical help, tracing missing children, emotional support & guidance etc. During the course of intervention, CHILDLINE has faced several hurdles in handling the cases. Some of the difficulties faced by the team members and staff are listed.

- ***Shelter Homes -*** There is a shortage of shelter facilities for mentally challenged children. The already existing shelter homes refuse to admit these children even when referred by the Child Welfare Committees (CWC). In case of these children, assistance is needed for basic activities such as bathing, feeding, toilet etc; shelter homes refuse to admit them on these grounds and state that they do not have staff to look after them. Even when children do get admitted, the shelter home staffs demand after a few days to take the child away.

- ***Difficulty in availing an IQ certificate -*** Shelter homes and CWC members request for an IQ certificate to certify that the child is mentally challenged; team members face difficulty in availing these certificates. One, it takes time to get these certificates and until these certificates are made the team faces the challenge of arranging for shelter for the child, as the shelter home would not accommodate until a certificate is received. Secondly, in some of the districts the responsible personnel who issues the certificate is not available. Hence it is very difficult to get an IQ/ disability certificate.

- ***Information on Services -*** No referral/resource directory is available with information of services for the disabled.

- ***Lack of cooperation*** from the allied systems (medical, law enforcement system) – At times the child is just dumped with CHILDLINE. Hospitals refuse to keep the children for longer period; once the primary treatment is provided they want the child to be taken away. At times they demand for a memo or letter from the police for treatment/admission.

- ***Lack of information –*** Often the children are unable to communicate and give any authentic information of their whereabouts, such as their parent's name, home address, or any landmarks that could help the team to trace the family.

Programmes and Policies for Protection of Rights of Mentally Challenged children

- 75% of the disabilities are preventable. The formative years of children, right from conception to the initial years of childhood are very critical and greater focus needs to be given during this period. The pre-birth needs of children, which are normally met through the health of the mother, needs to be addressed. The Integrated Child Development Services (ICDS) program of the Government of India currently addresses this aspect – perhaps the tracking of maternal health amongst the poorest sections of the population needs greater focus – both in terms of communication as well as nutritive/health care support.
- Awareness on facilities available for treating mentally challenged children, and of their rights should be provided. The proposed district Child Protection Committees (under ICPS) needs to coordinate with local implementers of ICDS to deliver this service to such families who are classified as “high risk” for mentally challenged children.
- The schemes/provisions provided by the Government are not easily accessible and take a long time in processing. There is a need for single window system for implementation of the various schemes and services for the welfare and rehabilitation of the disabled.
- Sensitization programmes should be organized for the concerned staff of the Government departments to facilitate speedy implementation of schemes and provisions.
- Parents and teachers have expressed that following the death of the parents the responsibility of looking after the child falls on the siblings or relatives. And it’s not guaranteed that they would be taken care of well. Social security provisions should be made available following the death of the parents/guardians.
- Need for short-term and long-term shelter. Regular shelter homes for children do not take the mentally challenged children, as they require special care and attention. Efforts have to be made to take in children with special needs with the normal children and facilitate the process of re-integration into the mainstream society.

Institutional Support

- Due to poor economic conditions children are deprived of nutritious food, are unable to get access to better health care facilities, and are exposed to disease producing conditions and environmental hazards.
- It also deprives children from accessing facilities such as cultural, recreational and day-to-day experiences, which are very essential for their holistic development. Such under-stimulations can result in irreversible damage and can serve as a cause of Mental Retardation. In Indian conditions this has proved to be an important causative factor.
- The Mid-Day Meal Scheme has shown positive impact in enrollment and retention of children in schools. Mid-Day Meal should also be made available for children in special schools as a means to encourage parents to send their child to the schools.
- In the rural areas motivation level of children is very low and parents too are not interested in sending their children to school. Hence teachers have to personally go and get the children to school often from distant places. Additional financial benefits to teachers in the rural areas.
- Transport facility should be provided for children commuting from school to residence, especially for the girl child. Many of the parents expressed apprehension in sending their daughters alone to the school fearing abuse.

Sensitization and Awareness

- For most of the parents school was the only contact point from where they gained information and shared their concerns with the teachers and other parents. There were no support groups that met on a regular basis. There is a need for the formation of Parent Support Group, so that they could share their concerns and issues. This would also function as a therapeutic group, where parents support each other.
- Early intervention is very essential in identifying a mentally challenged child. Sensitization programmes for the medical fraternity should be organized to help doctors communicate to the parents the status of the child at the earliest. It is essential to identify the child's condition instead of pushing the parents towards "window shopping" where they keep visiting numerous doctors in hope of finding some treatment to cure their child.
- Sensitization and awareness programmes should be organized at various levels for different target groups such as Anganwadi teachers, school teachers, community at large.
- Network with the media. Media can play a supportive role in educating and sensitizing the public on the issue and work towards attitudinal change.

Implications for CHILDLINE 1098

- Teachers at school expressed that greater awareness on CHILDILNE 1098 service needs to be done; and hence the service should be implemented in the school so that parents can benefit from the service.
- Expectations of assistance from CHILDLINE ranged from providing emergency medical treatment, teaching assistance, providing guidance & information, tracking missing children and recreation facilities. CHILDLINE should network and co-ordinate with organizations to make these services available to children.
- Capacity building trainings/workshops for CHILDLINE staff to cope with issues/problems of mentally challenged children.
- Interstate meet of CHILDLINE partners and allied system should be held to discuss the problems and needs of mentally challenged children and parents.
- Collate data from all 82 CHILDLINEs on mentally challenged children and related issues for advocacy.
- Resource Directory consisting of information on Legal provisions, Schemes, Policies and list of institutions/organizations/schools for Mentally Challenged Children with details on intake policy, eligibility (age, sex, degree of retardation), thrust area (education, vocational training, shelter) etc.
- Research – CHILDLINE India Foundation should look at the prospect of exploring the Child Rights and Protection issues of mentally challenged children.

Annexure I - Consent Form

CHILDLINE India Foundation

2nd Floor, Nanachowk Municipal School, Frere Bridge,
Low Level, Near Grant Road Station, Mumbai-400007

Children at Risk: A Study to Explore the Possibility of CHILDLINE Intervention

Mentally Challenge Children:

Interview Schedule

Hello. I am here on behalf of CHILDLINE India Foundation, Mumbai. CHILDLINE-1098 is India's first toll-free Tele-helpline service for children in need of care and protection. CHILDLINE is a National level programme of Child protection operating in 73 cities. Till date CHILDLINE has received approximately 10 million calls and worked with 4 million children in need.

Children calling CHILDLINE usually call when they are in need or in emergency, but there are some groups who are forever in dire situation, forever living in emergency. We are conducting a study that will explore the situation of mentally challenged children, availability of services, their rights and possibility of CHILDLINE intervention for this group of children.

You have been selected as respondent for the study. Few questions will be asked from you that require 45 minutes to 1 hour. You are free to stop the interview any time in between.

All the information collected will be used only for research purpose and your identity will be kept confidential.

Name of the Interviewer:

Signature (with date):

Annexure II - Parent Schedule

Q. No प्रश्नक्रमांक	Question प्रश्न	Coding
I.	**CHILD PROFILE मुलाचा तपशिल**	
1.1	Location जागा :	District जिल्हा:..... Taluka तालुका:..... Village गाव:.....
1.2	Relationship to the child मुलाशी नाते :	☐ Father वडिल .....1 Mother आई .....2 Other इतर .....3 Specify नमुद करा .....
1.3	Name of the Child (Optional) : मुलाचे नाव (ऐच्छिक)	.....
1.4	Age (in years) वय (वर्षे) :	☐☐
1.5	Sex लिंग :	☐ Male पुरुष .....1 Female स्त्री 2
1.6	Degree of Retardation शैक्षणिक अर्हता :	☐ Mild सौम्य .....1 Moderate मध्यम .....2 Severe प्रखर 3
1.7	What is the IQ of your child? मुलाचा बुध्धांक	☐☐
1.8	Religion धर्म :	☐ Hindu हिंदू .....1 Muslim मुस्लिम .....2 Christian ख्रिश्चन .....3 Others इतर .....4 Specify नमुद करा .....

1.9 Caste जात :

☐

Schedule Caste मागासवर्गिय 1

Schedule Tribe मागासजमाती 2

Other Backward Class इतर मागासवर्गिय ..3

General सर्वसाधारण 4

Other इतर 5

Specify नमुद करा .....

1.10 Type of family कुटुंब प्रकार :

☐

Nuclear विभक्त 1

Joint एकत्र 2

1.11. **Family Constellation** :

Sl. No	**Name** नाव	**Relationship with Child** मुलाशा नाते	**Age** वय	**Sex** लिंग	**Education** शिक्षण	**Occupation** धंदा	**Annual Income (Apprx)** साधारण वार्षिक उत्पन्न
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							

1.12 Is the house own or rented :
घर मालकी हक्कावर का भाडे तत्वावर

☐

Own स्वत:चे 1

Rented भाड्याचे 2

1.13 Type of dwelling जागेचे स्वरुप :

☐

Kutcha कच्चे 1

Pucca पक्का 2

Semi-pucca साधारण 3

II. FACTORS RELATED TO BIRTH जन्मासंबंधीची तत्त्वे

1.14 Anyone in the family having similar condition? ☐
कुटुंबातील आणखी कुणी व्यक्ती मानसिक रित्या आजारी आहे का?

Yes होय 1

No नाही 2

1.15 If yes, how is he/she related to the child?
जर हो अशा व्यक्तीचा मुलाशी नातेसंबंध?

_____

_____

1.16 Specify the nature of the condition.
मुलाच्या मानसिक आजाराचे सविस्तर वर्णन करा.

_____

_____

1.17 What was the age of the mother when the child was conceived? ☐☐
मुलाच्या जन्माच्या वेळी मातेचे वय

1.18 Were you ill at anytime during pregnancy? ☐
गर्भारपणी तुम्हाला कोणता आजार झाला होता?

Yes होय 1

No नाही 2

1.19 If yes, specify जर असल्यास, नमुद करा.

_____

_____

1.20 What treatment was taken during pregnancy? ☐
गरोदरपणी कोणते उपचार घेतलेत?

Consulted Doctor 1
वैद्यकीय अधिकऱ्यांशी सल्लामसलत

Home Remedy..... 2
घरगुती उपचार

Quacks 3

Local pandit, black magic..... 4
जारण-तारण उपचार (साधुद्वारे)

1.21 Were you taking any kind of medications during pregnancy?
गर्भारिअवस्थेतील औषधोपचार घेतले काय?

☐

Yes होय 1

No नाही 2

1.22 If Yes, for what. Specify.
जर असल्यास, कशासाठी?

1.23 Were you emotionally stressed during the pregnancy?
गर्भारिअवस्थेत भावनिक दृष्ट्या तणावाखाली होता काय?

☐

Yes होय 1

No नाही 2

1.24 If Yes, specify
जर असल्यास, नमुद करा.

1.25 Was it a full term pregnancy?
पूर्ण अवस्थेतील गर्भार अवस्था होती का?

☐

Yes होय 1

No नाही 2

1.26 If No, Specify?
नसल्यास नमुद करा.

1.27 Type of Delivery.
प्रसुती अवस्था.

☐

Normal सर्वसाधारण 1

Cesearean शस्त्रक्रियेद्वारे 2

1.28 Any complication during the delivery?
प्रसुतीच्या वेळी काही अडचणी उद्‌भवल्या होत्या का? .....

1.29 What was the weight of the baby when born? (Weight in Kgs)
जन्माच्या वेळचे बालकाचे वजन (वजन किलोग्रॅम)

☐☐ ☐☐

III. REACTION ABOUT THE BIRTH जन्मानंतरची प्रतिक्रिया

1.30 When did you first come to know that your child is mentally challenged?
मुल मतिमंद आहे हे तुम्हाला पहिल्यांदा केव्हा कळले?

1.31 To whom did you take your child to
तुम्ही मुलाला कोणाकडे घेऊन गेलात ☐

Psychiatrist मनोरुग्ण तज्ञ 1

Psychologist मानसोपचार तज्ञ 2

Neurologist मेंदू तज्ञ 3

1.32 How many doctors did you consult?
किती डॉक्टरांचा सल्ला घेतलात?

1.33 Were the doctors helpful?
डॉक्टरांची काही मदत झाली का?

1.34 What according to you is the cause for your child's retardation?
बालक मतिमंद असल्याचे कारण तुम्हास काय वाटते?

1.35 How long did it take for you to accept your child fully?
तुमच्या मतिमंद मुलाचा पूर्णत: स्विकार करण्यासाठी तुम्हाला किती वेळ लागला.

1.36 Who brought it to your notice?
मुलाची मानसिक स्थिती तुम्हाला कोणी लक्षात आणून दिली.

1.37 What was your first reaction? (Multiple Options)
तुमची पहिली प्रतिक्रिया कोणती होती?

Denial नकारात्मक ..... A

Anger क्रोध (राग) ..... B

Shock धक्का C

Sorrow दु:ख ..... D

Any other इतर कोणती .....E

Specify नमुद करा .....

1.38 Whom did you hold responsible for the disability?
ह्या व्यंगाबाबत तुम्ही कोणाला दोषी धराल?

☐

Self स्वत: 1

Spouse पती 2

Past sins पापकर्म 3

Doctor वैद्यकीय अधिकारी 4

None कोणी नाही 5

Any Other इतर कोणी 6

Specify नमुद करा .....

IV ATTITUDE TOWARDS THE CHILD मुलासंबंधी तुमचे वर्तन

1.39 If you had a male/female child, instead how would you feel?
जर तुम्हाला मुलगा किंवा मुलगी असती तर तुम्हाला काय वाटले असते?

_____

_____

1.40 Would you have preferred having a male child instead?
मुलगी ऐवजी मुलगा असता तर तुम्ही पसंद केला असता का?

_____

_____

1.41 Is your other child sympathetic towards him/her?
तुमचे दुसरे मुल अशा मुलाबाबत अथवा मुलीबाबत सहानुभूती दाखविते का?

☐

Yes होय 1

No नाही 2

1.41 Do you feel inferior due to your son/daughter?
तुम्हाला तुमच्या मुलाबाबत अथवा मुलीबाबत न्युनता वाटते का?

☐

Yes होय 1

No नाही 2

1.42 Do you take your child at social gatherings (religious/family gatherings)?
तुम्ही तुमच्या मुलाला सामाजिक कार्यक्रमास नेता का? (धार्मिक/कौटुंबिक कार्यक्रम) ☐

Yes होय 1

No नाही 2

1.43 If yes, how often?
जर असेल तर किती वेळा?

_____

_____

1.44 If No, why?
जर नसल्यास का?

_____

_____

1.45 Do you introduce your child at gatherings?
सम्मेलनामध्ये तुम्ही तुमच्या मुलाची ओळख करुन द्याल का? ☐

Yes होय 1

No नाही 2

1.46 Do you allow your child to interact and play with other children?
तुम्ही तुमच्या मुलाला इतर मुलांमध्ये मिसळण्यास आणि खेळण्यास परवानगी द्याल का? ☐

Yes होय 1

No नाही 2

1.47 If yes, what are the benefits you have seen as a result of the interaction?
जर होय असेल तर त्याच्या मिसळण्यामुळे तुमच्या मुलामध्ये कोणते फायदे दिसले का?

_____

_____

1.48 If No, Why?
जर नाही, का?

_____

1.49 Do you feel your child a hindrance to your other children's wedding?
तुम्हाला वाटते कां की तुमच्या इतर मुलांच्या लग्नात या मुलाचा अडथळा येईल? ☐

Yes होय 1

No नाही 2

1.50 If Yes, Why?
जर होय, का?

_____

_____

1.51 Do you think your child's condition can be improved?
तुमच्या मुलाची ही स्थिती सुधारेल असे तुम्हाला वाटते का? ☐

Yes होय 1

No नाही 2

1.52 If Yes, to what extent and how?
जर होय, असेल तर कुठपर्यंत आणि कशी?

_____

_____

1.53 If No, Why?
जर नाही, का?

_____

_____

1.54 Do you spend time with child when he/she returns from the school?
तुमचा मुलगा/मुलगी शाळेतून घरी आल्यावर त्याच्या/तिच्यासाठी वेळ देता का? ☐

Yes होय 1

No नाही 2

1.55 If Yes, how?
जर होय, कसा?

1.56 Does anybody in the family share the responsibility of looking after the child?
कुटुंबातील इतर त्या मुलाची देखभाल करण्याची जबाबदारी घेतात का?

V EDUCATION शिक्षण

1.57 How did you come to know of the special school?
यांच्यासाठी खास शाळा असतात हे तुमच्या कसे लक्षात आले.

1.58 Did you have any problems in the admission?
शाळेत प्रवेश घेतेवेळी तुम्हाला काही समस्या आल्या का?

1.59 Did he/she go to any other school before the present?
ह्या शाळेपूर्वी तो/ती दुसऱ्या शाळेत जात होता/होती का? ☐

Yes होय 1

No नाही 2

1.60 If Yes, Which?
जर होय, कोणत्या? ☐

Normal सर्वसाधारण 1

Special School खास शाळा 2

1.61 Till what standard did the child go to the normal school?
कोणत्या वर्गापर्यंत तुमचे मूल सर्वसाधारण शाळेत जात होते?

1.62 Is he/she happy with the school?
त्याला/तिला शाळा आवडते का? ☐

Yes होय 1

No नाही 2

1.63 Does he/she get along well with the teacher/other students?
तो/ती शिक्षक आणि इतर विद्यार्थ्यांमध्ये मिसळतो का?

☐

Yes होय 1

No नाही 2

1.64 If No, why?
जर नाही, का?

_____

_____

1.65 Do you go to meet the teacher?
तुम्ही शिक्षकांना भेटायला जाता का?

☐

Yes होय 1

No नाही 2

1.66 If Yes, how often?
जर होय, केव्हा? किती वेळा?

_____

_____

1.67 If No, Why?
जर नाही, का?

_____

_____

1.68 Are you happy with the school?
त्या शाळेसंबंधी तुम्ही समाधानी आहात का?

☐

Yes होय 1

No नाही 2

1.69 If No, Why?
जर नाही, का?

_____

_____

1.70 Do you suggest any changes?
तुम्ही काही बदल सुचवू इच्छिता का?

1.71 Who takes responsibility regarding the child's progress in school?
शाळेमध्ये मुलांच्या प्रगतीची जबाबदारी कोण घेतो?

1.72 Do you think your child has improved ever since he/she has started coming to school
शाळेमध्ये गेल्यापासून त्याच्या/तिच्या मध्ये काही सुधारणा झाली का? ☐

Yes होय 1

No नाही 2

1.73 Describe in brief the changes you have observed in your child post joining the school?
शाळेत गेल्यापासून तुमच्या मुलामध्ये कोणते बदल घडून आले?

VI AWARENESS ABOUT MENTALLY CHALLENGED मतीमंदाबद्दल जागृकता

1.74 What according to you causes Mental Retardation
मतीमंद मुलासंबंधी कोणती कारणे असतील?

1.75 Which are the sources from which you have gained information about different aspects of Mental Retardation?
मतीमंदांच्या विविध पैलूंबाबत माहिती तुम्ही कोणकोणत्या माध्यामातून मिळवली?

1.76 Have you read anything about Mental Retardation in any book, magazine or newspaper? Please explain in detail.
मतीमंद मुलांबद्दल पुस्तक, मासिक किंवा वर्तमान पत्रामध्ये काही तुमच्या वाचनात आले का? कृपया सविस्तर सांगा.

1.77 Have you seen or listened to any programme on Mental Retardation on radio/TV film? Please explain in detail
मतीमंद मुलांबद्दल तुम्ही रेडिओ/टेलीव्हीजन वर काही ऐकले किंवा पाहिले आहे का? कृपया सविस्तर सांगा.

_____

_____

VII ACCESS TO SERVICES सेवेची सोय

1.78 Do you know of the various services (residential/special schools) available in and around your area for mentally challenged children?
मतीमंद मुलांसाठी तुमच्या आजूबाजूला शाळा किंवा संस्थेची अशी सोय आहे का? ☐

Yes होय 1

No नाही 2

1.79 If yes, what are they?
जर आहे, कोणत्या?

_____

_____

1.80 Are you aware of any financial provisions/schemes that are available for mentally challenged?
मतीमंद मुलांसाठी आर्थिक तजवीज किंवा योजनांबद्दल तुम्हाला माहिती आहे का? ☐

Yes होय 1

No नाही 2

1.81 Have you received/availed the benefits of the services for your child?
त्या सेवेचा तुमच्या मुलाला फायदा झाला का? ☐

Yes होय 1

No नाही 2

1.82 Are you aware of any legal provisions available in India for mentally challenged
भारतामध्ये मतीमंद मुलांसाठींच्या कायद्याच्या तजवीजीबाबत तुम्हाला माहिती आहे का? ☐

Yes होय 1

No नाही 2

1.83 Are you aware of any help line service for children?
मुलांसाठी काही सहाय्यक दुरध्वनी सेवांबाबत तुम्हाला माहिती आहे का?

☐

Yes होय 1

No नाही 2

1.84 If yes what do you know about the help line services?
जर होय, तुम्हाला कोणत्या सहाय्यक दुरध्वनी सेवेविषयी माहीती आहे?

_____

_____

1.85 If No what kind of help line service would you like?
जर नाही, तर कोणत्या प्रकारची सहाय्यक दुरध्वनी सेवा असावी असे तुम्हाला वाटते?

_____

_____

1.86 Are you aware of the rights of the mentally challenged children?
मतीमंद मुलांच्या हक्कांबद्दल तुम्हाला काही माहीती आहे का?

_____

_____

VIII PARTICIPATION IN PARENT TEACHER MEETS/ SUPPORT GROUPS
पालक-शिक्षक सभा/इतर मदत संस्थामध्ये तुमचा सहभाग.

1.87 Do you have Parent Teacher Meetings in the school?
पालक-शिक्षक सभा होतात का?

☐

Yes होय 1

No नाही 2

1.88 Are you a part of any support Group/Associations?
तुम्ही अशा संस्थेचे/किंवा सहाय्य केंद्राचे सभासद आहात का?

☐

Yes होय 1

No नाही 2

1.89 If Yes, What? Give details
जर होय, कोणत्या? सविस्तर सांगा.

_____

_____

1.90 How often do you attend the meetings?
किती वेळा तुम्ही सभेला गेला?

1.91 What are the issues discussed in the meetings?
सभेमध्ये कोणकोणत्या विषयांवर चर्चा झाली.

1.92 Do you find these meetings are useful? ☐
या सभा उपयुक्त आहेत असे तुम्हाला वाटते का?

Yes होय 1

No नाही 2

1.93 If yes what are the advantages of such meetings?
असल्यास या सभांमुळे कोणते फायदे झाले?

1.94 Have these meetings brought any changes in you? ☐
या सभांमुळे तुमच्यामध्ये काही बदल घडून आला का?

Yes होय 1

No नाही 2

1.95 If yes, what are the changes?
जर होय, काय बदल घडला?

1.96 What are your expectations from such meetings? Specify
या सभांकडून तुमच्या काय अपेक्षा आहेत? नमूद करा.

1.97 Have you attended other meetings where you met other parents of children with Mental Retardation? ☐

या व्यतिरिक्त इतर सभेत तुम्ही मतीमंद मुलांच्या संपर्कात आलात का?

Yes होय 1

No नाही 2

1.98 Where did you attend such meeting?
अशा सभेला तुम्ही कोणत्या ठिकाणी हजर राहीलात?

_____

_____

1.99 Do you feel that if there is recurrent meeting among parents, it would help the parents deal with the child better?
अशा प्रकारच्या पालकांच्या सभा वरचेवर घेतल्याने त्या मुलांच्या बद्दल चांगला दृष्टीकोन होण्यास मदत होईल का?

☐

Yes होय 1

No नाही 2

1.100 If Yes, How?
जर होय असेल तर कसे

_____

_____

IX PRESENT CONDITION

1.101 Do you see any progress in the child after admitting him/her to the school?
आताची स्थिती अशाप्रकारच्या शाळेमध्ये प्रवेश घेतल्याने मुलामध्ये काही प्रगती झाली का?

☐

Yes होय 1

No नाही 2

1.102 Can your child do the following without your help?
खालील गोष्टी तुमचे मूल तुमच्या मदतीशिवाय करु शकेल का?

	Yes	No
Wash hands हात धुणे	1	2
Dress self स्वत: पोषाक करेल	1	2
Comb hair केस विंचरणे	1	2
Brush teeth दात घासणे	1	2
Toilet शौचास जाणे	1	2
Feed self स्वत: जेवणे	1	2

1.103 How do you see the future of your child? (Self Care, Economic stability, Old age)
तुम्ही तुमच्या मुलाचे भविष्य कसे पाहता (स्वत:ची काळजी, आर्थिक स्थैर्य, म्हातारपण)

Annexure III

Institution Schedule

1. Name of the Institution संस्थेचे नाव:
2. Year of Establishment स्थापनेचे वर्ष:
3. Contact Details संपर्काचा तपशील:

   Address पत्ता:

   Phone Number दूरध्वनी क्रमांक:

   Fax फॅक्स:

   Email id ई-मेल:

   Website वेबसाईट:
4. Background for establishment संस्थेचा पूर्व इतिहास:

5. Status of the Institute. (Government/Private) संस्थेचे स्वरुप (शासकीय/नीमशासकीय):

6. Total number of children एकूण मुलांची संख्या:

   Boys मुले: Girls मुली:

7. What is the staff strength? कर्मचारी संख्या किती?

8. Intake criteria (What is the age group and the degree of retardation)
वयाचा व शैक्षणिक पात्रतेचा निकष

9. What is the intake procedure? निवड प्रक्रीया कशी आहे?

10. How do the parents approach the institution? पालक संस्थेशी कशा प्रकारे संपर्क साधतात?

Hospital शुश्रृशालय/रुग्णालय:

School teachers शिक्षक:

Neighbours शेजारी:

Social Workers समाजसेवक:

Self स्वत::

11. Does the institution provide Residential or Non-residential facility?
संस्था निवासाची व्यवस्था करते काय?

12. What are the facilities provided by the Institution under Residential/Non-residential care?
संस्था निवासात अथवा अनिवासात कोणत्या सोयी करते.

a.

b.

c.

d.

e.

f.

13. Does the institute provide any Vocational Course for the children?
संस्था व्यावसायिक प्रशिक्षण देत का?

14. If yes, what are they? जर असल्यास, कशा प्रकारचे?

15. Does the products have a market? उत्पादनाला बाजारपेठ आहे का?

16. Do the children go home for vacations? If yes, what is the duration? (For residential care)
सुट्टीकालीन मुले घरी जातात का? जात असल्यास त्याचा कालावधी?

17. What is the school timings? शाळेची वेळ?

18. Does the institution organize workshops/seminars for the parents and family members (siblings) of the child?
संस्था पालकांसाठी कार्यशाळा/शिबीरे आयोजित करते का?

Yes होय

No नाही

19. If yes what are they? जर असल्यास कोणती?

20. If No why? जर नसल्यास कां?

21. How is the response of the parents towards these workshops/ seminars?
कार्यशाळेला शिबीराला पालकांचा प्रतिसाद कशाप्रकारे असतो?

22. Do you find any change in their approach/ attitude towards the mentally challenged?
पालकांचा मतिमंदांकडे पाहण्याच्या दृष्टिकोनात तुम्हाला काही बदल दिसून आला का?

Yes होय

No नाही

23. If Yes, how?
जर असल्यास कसे?

24. If No, why? What would you do about this?
जर नसल्या तुम्ही काय कराल?

25. Does the institution organize any awareness programmes fo the community? Give details.
संस्था ह्या बाबतीत समाज जागृतीचे कार्यक्रम करते काय? तपशील सादर करावा.

26. What have been the changes post these programmes?
अशा कार्यक्रमामुळे कोणते बदल होतांना दिसतात?

27. What are the rights of the mentally challengd children?
मानसिक दृष्ट्या परिपूर्ण मुलांसाठी कोणते हक्क आहेत?

28. Are the provisions and facilities provided by the Government sufficient to address the issue of Mentally Challenged Children?
संस्था शासन अशा मुलांसाठी सोयी-सुविधा पुरवित त्या पुरेशा आहेत काय?

Yes होय

No नाही

29. If No, what changes do you suggest?
नसल्यास, कोणता बदल अपेक्षित आहे?

30. What are the problems faced by the institute?
संस्था कोणत्या प्रकारच्या अडिअडचणींना सामोरे जाते?

Annexure IV

Brief overview of Rights of the Disabled in the Constitution of India

(Note: The information compiled in this section is for basic reference only. It is not a complete list of all information- this information is easily and widely available)

Though "Disability" is not defined in the Constitution of India, it clearly states that no citizen shall suffer any disability on the ground of his religious beliefs, gender, race, caste, sex, place of birth or any of them in regard to their access to public places, shops and right use of wells, tanks, etc.

The Constitution of India applies uniformly to all the citizens' irrespective of whether they are healthy and normal or disabled (physically or mentally) and irrespective of religion, caste, gender, creed etc.

However there is special social group for whom special legislations can be made. This special group includes all women, children, and those belonging to socially and educationally backward classes.[1]

Sl.No	Constitution of India	
Fundamental Rights The constitution secures to every citizens including the disabled: justice, liberty of thought, expression, belief, faith, and worship, equality of status and opportunity and for the promotion of fraternity.		
1.	Equality before law, Article 14	Puts forth that the State shall not deny to any person equality before the law or the equal protection of the laws within the territory of India. This holds true for the disabled also.
2.	Prohibition of discrimination on grounds of religion, race, caste, sex or place of birth, Article 15 (1)	States that no citizen shall be discriminated on the grounds of religion, race, caste, sex, place of birth or any of them. Also on these grounds they cannot be subjected to any disability, liability, restriction or condition with regard access to shops, public restaurants, hotels, and places of entertainment.

1. Rehabilitation Council of India – Legal Rights of Persons with Disability – India, 2004, New Delhi

3.	Abolition of Untouchability, Article 17	States that “Untouchability” is abolished and its practice in any form is forbidden. And any disability arising out of “Untouchability’’ is an offence punishable in accordance with law.
4.	Article 21	The Indian Constitution states that no person shall be deprived of his life or personal liberty except according to procedure established by law.
5.	Prohibition of traffic in human beings and forced labour, Article 23	Prohibits traffic in human beings and enforced beggary and other similar forms of forced labour and any contravention of this provision is an offence punishable under the law.
6.	Prohibition of employment of children in factories, etc, Article 24	No child below the age of fourteen years shall be employed to work in any factory or mine or engaged in any other hazardous employment.
7.	Article 32	Confers the right on an individual to move to the Supreme Court for enforcement of the rights.
8.	Right to work, to education and to public assistance in certain cases, Article 41	The State shall within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want

Educational Rights		
9.	Right to Education, Article 21	States that the State shall provide free and compulsory education to all children of the age group six to fourteen years in such manner as the state, by law, may determine.
10.	As per Article 29 (2)	No citizen shall be denied admission into any educational institution maintained by the State or receiving aid out of State funds on grounds only of religion, race, caste, language or any of them.
11.	Provision for early childhood care and education to children below the age of six years, Article 45	The State shall endeavour to provide early childhood care and education for all children until they complete the age of six years
Health Rights		
12.	Duty of the State to raise the level of nutrition and the Standard of living and to improve public health, Article 47	The State shall regard the raising of the level of nutrition and the standard of living of its people and the improvement of public health as among its primary duties

(Constitution of India, V.N. Shukla, March 2007)

"The disabled also have by implications certain rights, which though not enforceable, provide effective guidelines for the government to make provisions including legislative provisions for the disabled. Some of them are:

- The State shall endeavor to provide for free and compulsory education for all children until they complete the age of fourteen years.
- The State shall endeavor to provide early childhood care and education for all children until the age of six years.
- Every citizen who is a parent or guardian has to provide opportunities for education to his child or, as the case may be a ward between the age of six and fourteen years.

Primary Education Act has been enacted by various States to provide for free primary education in the respective States. And it is the obligation of every local authority (Municipal, Corporation, Municipal Committee or Cantonment Board) to provide for compulsory primary education for children within its jurisdiction. Schools can also be set up under the above Act for imparting primary education to children suffering from physical and mental disability.

Apart from the Primary Education Act there is also the Secondary Education Act for imparting education higher than the primary education. These schools are also aided by the government and special schools for the disabled can be set up"[2].

Apart from the Constitutional provisions for the disabled (though not specifically mentioned) there are certain Acts that too that are specially made for the disabled.

The Government of India has enacted three legislations for persons with disabilities viz. (i) Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which provides for education, employment, creation of barrier free environment, social security, etc. (ii) National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999 has provisions for legal guardianship of the four categories and creation of enabling environment for as much independent living as possible. (iii) Rehabilitation Council of India Act, 1992 deals with the development of manpower for providing rehabilitation services.

2. Legal Rights of Persons with Disability, Rehabilitation Council of India, 2004

The Persons with Disabilities (Equal Opportunities, protection Of Rights and Full Participation) ACT, 1995 [3]

The persons with disabilities Act seeks to give effect to the Proclamation on the full participation and equality of the people with disabilities. It is an Act to give effect to the Proclamation on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region.

The meeting to launch the Asian and Pacific Decade of Disabled Persons 1993-2002, convened by the Economic and Social Commission for Asia and Pacific was held at Beijing on 1st to 5th December 1992, and adopted the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region.

"The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995" came into force on February 7, 1996. This law is an important landmark and is a significant step in the direction of ensuring equal opportunities for people with disabilities and their full participation in the nation building. The Act provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc.

Main Provisions of the Act:

- Preventions and Detection of Disabilities
- Education
- Employment
- Non-Discrimination
- Research and Manpower Development
- Affirmative Action
- Social Security
- Grievance Redressal

Other Policies and Acts instituted within the Constitution of India to guarantee the Rights of persons and children with disabilities:

3. http://socialjustice.nic.in/disabled/act.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999[4]

An Act to provide for the constitution of a body at the national level for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and for matters connected therewith or incidental thereto.

The National Trust for welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 came into force w.e.f. 30th December, 1999. The National Trust supports programmes which promote independence, facilitate guardianship where necessary and address the concerns of those special persons who do not have their family support. The Trust also seeks to strengthen families and protect the interest of persons with autism, cerebral palsy, mental retardation and multiple disabilities after the death of their parents.

It is an important Act as it addresses the concerns of the parents and family members of the people with disabilities. It addresses the issue of what kind of provision can be made for people with disabilities during their lives and when the parents/family members are no longer there to look after them. The Act is only intended for the benefit of persons with Cerebral Palsy, Mental Retardation, Autism and Multiple disabilities.

The act ideates the setting up of a Trust that will be managed by a Board of Trustees. The Board will decide on the matters of implementation of the act. Apart from this Board the other implanting bodies include the Local Level Committee that function at the state/or the district levels.

Rehabilitation Council of India Act 1992 [5]

An Act for regulating the training of rehabilitation professionals and the maintenance of a Central Rehabilitation Register and for matters connected with disability rehabilitation.

The Rehabilitation Council of India was set up as a registered society in 1986 under the aegis of the Ministry of Social Justice & Empowerment to standardize and maintain uniform standards of training of professionals. The Parliament enacted the Rehabilitation Council of India Act in 1992.

The RCI Act was amended by the Parliament in 2000 to make it more broad based. The Act casts onerous responsibility on the Council. It also prescribes

4. http://socialjustice.nic.in/disabled/
5. http://www.rehabcouncil.nic.in/council/council.htm

that any one delivering services to people with disabilities, who does not possess qualifications recognised by RCI, could be prosecuted. Thus the Council has the twin responsibility of standardizing and regulating the training of professional and personnel in the field of Rehabilitation and Special Education.

National Policy for Persons with Disabilities[6]

The National Policy recognizes that Persons with Disabilities are a valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. The Policy focuses on the following areas:

- Prevention of Disabilities
- Rehabilitation Measures
- Physical Rehabilitation Strategies
  - Early Detection and Intervention
  - Counseling & Medical Rehabilitation
  - Assistive Devices
  - Development of Rehabilitation Professionals
- Education for Persons with Disabilities
- Economic Rehabilitation of Persons with Disabilities
  - Employment in Government Establishments
  - Wage employment in Private sector
  - Self-employment
- Barrier-free Environment
- Issue of Disability Certificates
- Social Security
- Promotion of Non-Governmental Organizations (NGOs)
- Collection of regular information on Persons with Disabilities
- Research
- Sports, Recreation and Cultural life
- Amendments to existing Acts dealing with the Persons with Disabilities

Under the National Policy for Persons with Disabilities, Children with disabilities are recognized as the most vulnerable group and in need of special attention. Bearing this in mind the Government would strive to:

1. Ensure right to care, protection and security for children with disabilities;

6. http://www.disabilityindia.org/nationalpolicyfordisable.cfm

2. Ensure the right to development with dignity and equality creating an enabling environment where children can exercise their rights, enjoy equal opportunities and full participation in accordance with various statutes.

3. Ensure inclusion and effective access to education, health, vocational training along with specialized rehabilitation services to children with disabilities.

4. Ensure the right to development as well as recognition of special needs and of care, and protection of children with severe disabilities.

The key ministries involved in the implementation and monitoring of the policies/ services related to vocational rehabilitation of the disabled people are listed below.

Government Organizations dealing with Disability in India

Name	Description
Ministry of Social Justice & Empowerment	Entrusted with the welfare of Persons with Disabilities (PWD). The basic objective of the policies, law and institutions on welfare system in India is to bring PWD into the mainstream of development by making them self-reliant.
Ministry of Health & Family Welfare	Implement health programs for prevention of disabilities like Leprosy, Blindness and Immunization. **Schemes**: • National Programme for Control of Blindness • National Programme for Prevention and Control of Deafness
Ministry of Urban Affairs & Poverty Alleviation	It is mainly concerned with the provision of building standards for Persons with Disabilities as provided under Section 46 of the Persons with Disability Act. The Ministry prepared the Model Building Bylaws, containing provisions for a barrier free environment along with guidelines and space standards and circulated the same to all the State Governments and Union Territories for adoption.
Ministry of Rural Development & Employment	The Ministry took the initiative under which three percent of the total subsidy budget under the Integrated Rural Development Program is earmarked for provision of revolving fund assistance of Rupees 25,000 to Persons with Disability self-help groups and disabled rural poor for carrying out activities of their choice.

Ministry of Human Resource Development	Deal with policy for education. The Department of Education undertakes activities for educating PWD, including implementing scheme for the Integrated Education of Disabled Children (IEDC) through State Education Departments, Autonomous Bodies and NGOs. 100% financial assistance is provided under the scheme for the education of children with Disabilities.
Ministry of Labour	The Ministry, through the Directorate General of Employment & Training (DGE & T) extends services to Persons with Disabilities through a number of schemes. DGE&T runs seventeen vocational rehabilitation centers for PWD throughout the country, covering all types of disabilities. It also runs Rural Rehabilitation Extension Centers and a Central Institute for Research & Training in employment services.
Ministry of Railways	Concerned with the provision for barrier-free facilities in railway office buildings and railway stations for PWD. It has also drawn up plans to modify entrances to railway coaches and provide facilities inside coaches for the PWD. Also extends fare concession to PWD.
Ministry of Civil Aviation	Provided barrier-free facilities at the airports. Also allow fare concession to PWD.
Department of Personnel & Training	Three- percent quota in Government for PWD has been reserved since 1977. After the enactment of the PWD Act, this quota has been extended to other sections of the Government.
Department of Science & Technology	Research and development projects funded by the Department on the development of assistive devices. It is also assisting in providing for low cost and standard aids/ appliances for PWD.
Department of Women & Child Development	Provide health education and immunization programs through the Integrated Child Development Scheme. Also provide training to workers at community health centers under the plan for prevention of disabilities, detection and in creating public awareness.

(***Source: Country Profile on Disability-India (March 2002), Japan International Cooperation Agency, Planning and Evaluation Department***)