Normal Childhood’s Response to Childhood of Mentally Challenged:
Aspirations and Ground Reality of Mentally Challenged Children

Study Report submitted in fulfilment of the
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Ensuring lasting change for children

BY

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“Our grief is not a failure to come to terms with disability, our dissatisfaction with our lives is not a personality defect but a sane response to the oppression we face.”

- J Morries

-From ‘DISABILITY: CHALLENGES VS RESPONSES

By Ali Baquer; Anjali Sharma)

“People are frequently said to be disabled when they fall outside an accepted norms or functions or behaviour, thus the concept of disability of ultimately rests upon a social judgements.”

- Sally French

“One of the biggest problems facing disabled people is stereotypes. If you portray people as objects of pity, in a mass medium like a telethon which has sixty million viewers, then it only reinforces those stereotypes.”

– James E. Williams, Jr.

-From ‘DISABILITY: CHALLENGES VS RESPONSES

By Ali Baquer; Anjali Sharma)
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ABBREVIATIONS AND GLOSSARY

Abbreviations

IQ       Intelligence Quotient
NGO     Non-Government Organizations
FGD     Focused Group Discussion
NIMH    National Institute for the Mentally Handicapped
TV      Television

Glossary

Mentally Challenged Children: This term is used for Mentally Retarded Children

Non-mentally Challenged Children: It means normal or able bodied except than mentally challenged children
AKNOWLEDGEMENTS

The main idea of this study emerged during my field-placement for my master in Social Work course, where I was placed in the workshop for mentally challenged children. This opportunity in the workshop of mentally challenged children provided me the conceptual background and opened new areas for further detailed enquiry for the present study. I acknowledge Prof. Anjali Maydeo from Karve Institute of Social Service, Pune and Mrs. Vidya Joshi, Head of workshop for mentally challenged of Dilasa Sevasadan Trust Pune for providing me this opportunity.

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I give my special thanks to CRY for supporting this study and providing me the opportunity to study the childhood of mentally challenged children, I specially thank, Vijayalakshmi Balakrishnan, Head Policy and Research, Puja Marwaha CRY CEO, Keith and Chhaya from CRY for their support.

Neela, my wife and Apada, my brother deserve for special thanks for their continuous encouragement, support and inputs in drafting this study-report. I reserve my special thoughts for my family and friends. Above all, I thank all respondents of my study, especially mentally challenged children and their parents, siblings and their teachers for spending their valuable time and sharing their experiences with me.

1st June 2011

Pune 411006

Eshwer B. Kale
SUMMARY OF THE STUDY
The Disability sector is the most ignored and vulnerable one, especially the mentally challenged children and adolescents. The aspirations of childhood, freedom of mobility and involvement in societal functions of mentally challenged children as compared to non-mentally challenged children are many times ignored and suppressed by family members, peer groups and society. Generally this happens due to stigma and labels attached to them due to being “mentally retarded”. At present there is very limited and poor qualitative literature available on this socially ignored issue of mentally challenged children’s childhood.

With this background by accepting qualitative paradigm the study explores, perceptions, nature and aspirations of mentally challenged children (from mild and moderate category) about their own childhood concept. As well as it also explore the views and perception of non-mentally children towards mentally challenged Children and the extent, layers and patterns of problems faced by mentally challenged children in their families and at societal level. The study use multi-stakeholder and multi-method approach to understand the ground reality of the proposed research concerns.

The key study findings and observation show that mentally challenged children do express their interest, likes, dislikes and future aspirations. Even few of them think about jobs, marriages, and homes. Common interest observed in these children is watching TV. Generally they are very close to their father and share joy, happiness, disinterest with him. Non-mentally challenged children give labels to mentally challenged children as Veda, kami-akkalecha (with low intelligence, foolish, unwise), and very few mentally challenged children have normal friends. Both, education and economic status of parent matters in dealing with such child but the parent’s education status have more positive impact compare to economic status. The presence of mentally challenged children at public places is generally avoided and they suffer from humiliation, abuse and teasing by able bodied people at public places. Stigma of being mental retardation also limits their opportunities in various fields. With these observations I recommend that, the whole
society should be sensitized and aware with the scientific information about the mental retardation and popular media has to play significant role in achieving it.
Chapter I

Introduction

The introductory chapter starts with discussion on the background of the study, and further discusses the structure of the report, where I give the basic idea of various chapters included in it. Further, I continue with discussions on the relevance of studying mentally challenged children’s childhood, Statement of the problem and the methodology adopted for the study and concludes this chapter with the limitations of the study.

1.1 Background of the Study

The Disability sector is the most ignored one, especially the Mentally Challenged people. Approximately 2.5 to 3 percent (only reported) of the global population is mentally retarded. Through there are few government support-facilities and institutional support provided by NGO sector for mentally challenged people they still remain most vulnerable and ignored part of society or our social life. Survey conducted in 2007, by Karnataka state Co-ordination committee of Parivar, an association of parents of mentally challenged find that eighty five per cent of mentally challenged are not covered by any of the service offered by government or private agencies. The mentally challenged children and adolescents are most vulnerable and ignored part of our community, they suffers from various behavioural, emotional, physical and psychological problems in their day to day life. The aspirations of childhood, freedom of mobility and express, and involvement in societal functions of mentally challenged children as compared to non-mentally challenged children are many times ignored and suppressed by family members, peer groups and by large society. Their mixing and participation in societal, cultural, institutional levels and programs many times is restricted directly or indirectly by parents and family due to stigma attached to these children of being ‘mentally retarded’. These children many times face the problem of social avoidance as well as avoidance in their families in family occasions and get together, in form of shutting them in a room for long

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1 Mental retardation is mentioned with various terms in literature such as mentally handicapped, mentally disabled, intellectually handicapped, etc.
period or may be for life long and not allowing them in touch with the outer world and not taking them for a walk or shop. At present there is very limited and poor qualitative literature available on this socially ignored issue of mentally challenged children’s childhood.

1.2 Structure of the Study

This report consists of five chapters, first chapter broadly discuss the statement of the research problem, rationale, objectives and methodology accepted for the study. Second chapter ‘Literature Review’ discusses the available literature on the research theme and discuss it in Indian context. It broadly discuss the concept, degrees, myths and misconceptions about mental retardation, and focuses on the history of discrimination to these children and end with the discussing the major policies and institutions formed for the betterment of mentally challenged people.

Chapter three and four share the data analysis and observations of the fieldwork done for the study. Chapter three discuss the aspirations, likes, dislikes and general perception about their goals in life and also discuss the family related issues and conclude with the detailed discussions on how non-mentally challenged children respond to mentally challenged children. Chapter four is about the overall discussion on the discrimination, abuse and violence faced at various levels by mentally challenged children at their home or family and society level. Finally, report ends with chapter five with summary of analysis and the ways forward towards the better social integration of mentally challenged children with few concrete recommendations.

1.3 Statement of Problem

In this section I discuss the extent or the population details of the mentally challenged people and especially mentally challenged children and then discuss the concept of social integration of mentally challenged children and obstacles in this process.

1.3.1 Extent of Mental Retardation in India
It is estimated that the overall population with disability in India is approximately over 90 million, of these 12 million are blind, 28.5 million are with low vision, 12 million are with speech and hearing defects, 6 million orthopedically handicapped, 24 million mentally retarded, 7.5 million mentally ill, 1.1 million leprosy cured (Baquer Ali and Anjali Sharma 1996).

A comprehensive country-wide sample survey of persons with disabilities was undertaken by National Sample Survey Organisation (NSSO) in its 36th round in 1981 at the request of the Ministry of Welfare which indicated that 1.8 per cent of the total population of the country has physical and sensory disabilities. No survey on mentally retarded persons was done at that time. However, surveys done by various research organisations indicate that about 2 - 2.5 per cent of the total population of the country has mental retardation. In a separate survey of children (age 0-14 years) with delayed mental development, it was found that 29 out of 1000 children in the rural areas had developmental delays which are usually associated with mental retardation. Approximately 3 per cent of the children between 0-14 years of age have developmental delays associated with mental retardation. According to Rehabilitation Council of India’s report on Manpower development (1996), estimated on the basis of the NSSO report, population of children with disabilities in the age group 5-14 was as follows

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locomotor Handicap</td>
<td>8.94 million</td>
</tr>
<tr>
<td>Hearing handicap</td>
<td>3.24 million</td>
</tr>
<tr>
<td>Speech handicap</td>
<td>1.96 million</td>
</tr>
<tr>
<td>Visual handicap</td>
<td>4.01 million</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>9 million</td>
</tr>
</tbody>
</table>


2 Even in few reports and studies percentage of mentally challenged children is mentioned up to 3 percent
Cerebral palsy 3 million

Source: Rehabilitation Council of India’s report on Manpower development (1996)

In most populations all over the world approximately two to three per cent of the population is expected to be mentally challenged. Mental handicap has being defined as a condition characterised by significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period. On this basis it can be estimated that there are nearly 24 million individuals in India with mental retardation, out of which approximately six million are moderately, severely or profoundly handicapped. Out of the 24 million, 0.8 million are adults over 20 years of age whereas 15 million are children below 10 years of age. (CBR Manual: Concept and Extent of disability in India)

1.3.2 Social Integration- Concept and Obstacles

Until recently, both the mentally challenged people and experiences of being challenged had been marginalized by most societies. The disciple of medicine and psychology were given the task of adjusting to the variety of problems presented by people with disabilities, who were either put away out of sight in large institutions or were forced to live ‘untouchable’, out of the conscious thinking of a larger body of society (Baquer Ali and Anjali Sharma 1996). India was not exception to these practices.

The entire question of integration and inclusion of mentally challenged people in society is, to a great extent, linked with what meaning society-its scholars and professionals, its lawmakers and bureaucrat, its disable and their families – gives to ‘disability’. If mentally challenged people looked upon as tragic victims of circumstances, and only in terms of their personal in adequacies and functional limitation, then it is not surprising that they are kept at a distance and are treated with pity as well as targets of charity. On the other hand, if mental retardation is seen as the social restriction and oppression by society then these people are identified as an uncared for and neglected group forced by social and
political processes to isolation, marginalization and alienation. This approach endorses the presence of social dimensions of the mental retardation. The real cause of individual’s inability to get access or mobile or get freedom of opportunities is found in the social and physical environment. The demand for integration and inclusion is in fact a protest against the oppression that the society has been exercising. The policies of welfare, the programmes aimed at alleviating the distress of mentally challenged people, the language used for them, all force these people to accept that they themselves are responsible for their conditions. The segregated existence of mentally retarded people over long periods of human history is the consequences of the insistence of society to regard them as ‘different or aliens’ and inflict stigma on them. Therefore, the issues of integration and inclusion cannot be understood simply in the context of the extent of retardation or disability but requires comprehension of a whole range of experiences from physical, social and psychological factors. Society’s old and deep seated discriminatory practices and attitudes against mentally challenged people are the major hurdles in the intergradations of them in society. Disability is essentially a social construct and reflects a flaw in the thinking processes of our society\(^3\). For example the child with mental retardation does not have a problem; the problem is rather with the surrounding, family and societal environment which prevents his mobility in the public places, to get inside or with the bus which stops him from riding in it or the non-disabled children who ignores him.

With above background, my epistemological assumption in the present study is that the birth of mentally challenged child or the retardation of individual acquired through accident or disease at a later stage in life present a challenge to the individual, family society. My ontological assumptions are that it is the non-mentally challenged who, either because of their ignorance or prejudices, actually disable person with handicaps and impairments. It is the society which discriminates against the mentally challenged and puts them into the categories considered it as deserving pity and charity. It is once again the society which built the cultural, physical, social, psychological and economic barriers

\(^3\) It differs from the only biological functioning of body.
so that the distance is created between it and people with mental retardation. Society robs them for their self respect, dignity and independence.

1.4 METHODOLOGY

Methodology section start with discussing the rationale for study and objective or research concerns of the study and proceed with methodology adopted for study and the details of data collection tools.

1.4.1 Rationale for and Objectives of the study

The focus of research in mental retardation in India has all along been dominated by medical models and research with these lines. The bibliographic study made by S. Venkatesan and VGD Vepuri in 1995, on the available literature on mental retardation across the world indicates 40.09 per cent of the total research compilations of 1095 titles are on medical aspects of mental retardation. (see Table 1.2)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>N</th>
<th>Percent</th>
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<tr>
<td>Medical</td>
<td>439</td>
<td>40.9</td>
</tr>
<tr>
<td>Psychological</td>
<td>194</td>
<td>17.72</td>
</tr>
<tr>
<td><strong>Psychosocial</strong></td>
<td><strong>122</strong></td>
<td><strong>11.4</strong></td>
</tr>
<tr>
<td>Policy issues</td>
<td>102</td>
<td>9.32</td>
</tr>
<tr>
<td>Psycho educational</td>
<td>94</td>
<td>8.58</td>
</tr>
<tr>
<td>Downs Syndrome</td>
<td>55</td>
<td>5.02</td>
</tr>
<tr>
<td>Prevalence</td>
<td>38</td>
<td>3.47</td>
</tr>
<tr>
<td>Services</td>
<td>26</td>
<td>3.37</td>
</tr>
<tr>
<td>Early intervention services</td>
<td>25</td>
<td>2.28</td>
</tr>
<tr>
<td>Total</td>
<td>1095</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: S. Venkatesan and VGD Vepuri 1995,
More significantly, research on preventive aspects and early intervention has taken backseat in the scenario of medical research on mental retardation. As regards to psychological aspect of mental retardation, research contributions have largely confined themselves to problems of diagnostic assessment and definition of mental handicaps.

The major area of considerable neglect is studies on parents, families of persons with mental handicaps. Wherein, the long term objective is to use parent or family resources for the purpose of welfare and rehabilitation of mentally handicapped people.

The available literature on the issue of mentally challenged children is mostly dominated by medical pathology and Psychological treatments (S. Venkatesan and VGD Vepuri 1995), generally it talks about the issues such as concepts of retardation, its causes and IQ based division, need of parental care, and various policies and schemes available on centre and state level in India. But, beyond that, it is silent on the practices and problems faced by these children in family and society level, as in many times they are denied, ignored and discriminated in participation, involvement and opportunities.

In this background, the current study aim,

1) To explore, perceptions, nature and aspirations of mentally challenged children about their own childhood concepts.
2) To explore the views and perception of non-mentally challenged children towards mentally challenged Children (Non-mentally challenged children’s response to childhood of mentally challenged.)
3) To explore, the extent, layers and patterns of problems faced by mentally challenged children in family and at societal level.

1.4.2 Process of Inquiry

I adopted a Qualitative Research Process Model for the purpose of the study. The process of inquiry in research began with my experiences and relationship in this field. In my Master of Social Work degree, I got an opportunity to work with and understand the life,
difficulties and challenges faced by the challenged children. It helped me to form a pedestal of gaining knowledge and insight about the challenges faced by these children. However, I did not develop this insight and perspective about the issue only on the basis of these experiences, but it played a significant role in developing my interest and curiosity to investigate the research concerns for present study.

I had ideas, experiences, knowledge and information about these children, but there was a need to sort them in an organized manner, which could be used for developing a basic understanding of researching the field. The process of Literature Review helped to start the process of researching the field. From the literature, I have therefore developed an in-depth understanding of the issue, which demands further research and inquiry about the gaps shown in the literature related to the aspirations of these children and how non-mentally challenged children respond to them.

1.4.3 Qualitative Research Process Model

The Qualitative research model provides a platform to understand a reality pertaining to a context. In this study, the context is equally important if one attempts to understand a particular social reality pertaining to mentally challenged children. Qualitative research provides the platform to understand the particular phenomenon by exploring the reason of its occurrence within the context. In qualitative research methodology, the focus is generally on the meaning of the subject of study and not on the frequency of the occurrence of that phenomenon. In this study, I am keen to analyze the processes of exclusion, discrimination and labelling of mentally challenged children at family and society level.

The qualitative research process precisely helps and supports this study because it allows the research process to be nonlinear, iterative, and responsive to the field situation and context specific. The process is non linear at every step and also between the steps so that we can respond to the field situation, accepting field reality, altering our own understanding to accept the data in its own context. The non linear approach also gives us
room to use our own experience in the field as source of knowledge and refers to the field practice as the experiences of collectives of the person.

1.4.4. Approach and Interpretive Paradigm

The research study follows a Case Study design, allowing a detailed analysis of findings from six case studies of mentally challenged children. To maintain the integrity of data parents of same six children and their school teachers/supervisors are also interviewed.

Case study as a research method is used for the purpose to gain understanding about instances of being labelled and discrimination, why such instances happened, incidences of difficulties in integrating them in society etc. it is an empirical inquiry that investigates a phenomenon within its real-life context.

Due to lack of studies specific to this area, I used an exploratory design to develop an understanding about the process of continued stigmatisation and discrimination of the challenged children and their families. Through case study approach I aimed at gaining further insight upon how and why these children are labelled and by whom, how the lives of individuals have been affected due to continued labelling. I collected data across six case studies of challenged children along with their families (parents and siblings) and made four in-depth interviews with their teachers at school.

I followed a Grounded Theory approach of Qualitative Research. The Grounded Theory refers to the theory emerging from within the raw data collected in the field in the form of case narratives and records. The grounded theory takes different cases as whole in which the variables interact as units to produce certain definite outcomes. If done well, this means that the resulting theory at least fits properly to the data it has emerged from. This contrasts with theory derived deductively from grand theory, without the help of data, and which could therefore turn out to fit no data at all.

This qualitative study made use of interpretive paradigm. The interpretive paradigm is characterized by a belief that reality is socially constructed, subjective, and influenced by...
culture, history, and views of the social world. The social world is viewed as an emergent social process created by the individual’s concerned. The paradigm tried to maintain objectivity while being the collector and interpreter of the data. Through this paradigm I observed an on-going phenomenon existing in society and affecting individuals and tried to understand individual behaviours.

1.4.5 Multi-Method and Multi-Stakeholder Approach of Data Collection

Reality is always multilayered, multidimensional and complex in nature and to explore the various facets of the reality, it needs multi-stakeholder and multi-method approach. Therefore, for the study multi-stakeholder and multi-method approach is applied in efforts to explore the research concerns and collect the data.

To explore the childhood of mentally challenged children and perceptions of non-mentally children about them various stakeholder respondents were identified and interviewed, consisting mentally challenged children (boys and girls), their parents and siblings, their teachers, and non-mentally children (boys and girls). At the same time quantitative data from these various stakeholders or respondents were collected using various methods of data collection such as in-depth interviews, focused group discussion and non-participant observation. The basic assumption behind the application of multi-stakeholder and multi-method approach was that it ensures and increase reliability in findings and validity of the study.

1.4.5.1 In-depth Interviews

In-depth unstructured interview as a technique to collect data is applied in study and the interviews were conducted with various types of respondents. Three school teacher/supervisors are interviewed at school, whereas one teacher is interviewed at his home because of suitability of his timing. Four mentally challenged children are interviewed in school, whereas two children due to their dropout from school from last few months are interviewed at their home. Parents of all six children are interviewed at their home; out of six in two cases both parents were present, whereas in two cases parent
along with siblings were present. Open ended questions were used as a technique to collect the data during the interview process. The participants were informed in prior about the purpose of the study and that they have the choice to withdraw in between of the interview as well, not to response on issue where they do not feel comfortable. The verbal an informed consent was also taken from participants for audio recording. In one case parent was not very comfortable with audio recording, so written notes were taken in this case. The interviews were carried out in a semi-structured manner; the process was a guided conversation rather than structured inquiries.

1.4.5.2 Focused Group Discussion

I conducted Four FGD, two with mentally challenged and two with non-disabled high school students. The responses of the participants were recorded which were later developed into a transcript for further analysis. I developed guidelines for conducting the FGD in prior. The set of open ended questions were also prepared in prior by the researcher. FGD with non-disabled children were conducted to develop understanding about their perceptions, experiences and understanding of mentally challenged children. Whereas FGDs with challenged children were conducted to assess their aspirations and explore the school, family and society level experiences.

Mentally Challenged Children engaged in exercise in FGD
1.4.5.3 Non-Participant Observation

As I got opportunity to spend much time with challenged children in school, I took this opportunity to keenly observe the interaction pattern of these students with each other and their teachers, their reactions and responses to the teachers. The school prayer, playing time on the ground and the lunch time were the major incidences to observe their behaviour. The family atmosphere and pattern of interaction with this student within family I could closely observed during the interviews of parents at their home.

1.4.5.4 Profile of Respondents:

The study is conducted with mentally challenged children in Pune city based school for mentally challenged in Maharashtra. The respondents of the study are belonging to various socio-economic backgrounds. The six cases of the study were chosen purposively after the in-depth interviews with teachers and FGDs with challenged children. The details about the profile of six cases are given below in table 1.3. Names of the respondents are changed for the purpose of confidentiality.

Table 1.3: Profile of Mentally Challenged Children Respondents

<table>
<thead>
<tr>
<th>No.</th>
<th>Name of Mentally Challenged Children</th>
<th>Age</th>
<th>Sex</th>
<th>IQ (in range)</th>
<th>Caste</th>
<th>Parents Occupation</th>
<th>Annual Income of family in Rs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>*Rajendra Dashrath Gaikwad</td>
<td>16</td>
<td>M</td>
<td>45-50</td>
<td>SC</td>
<td>Office Clerk</td>
<td>150000</td>
</tr>
<tr>
<td>2</td>
<td>*Hapij Yasin Shaikh</td>
<td>14</td>
<td>M</td>
<td>40-45</td>
<td>Muslim</td>
<td>Company Worker</td>
<td>120000</td>
</tr>
<tr>
<td>3</td>
<td>*Namdeo Ranuji Jadhav</td>
<td>17</td>
<td>M</td>
<td>35-40</td>
<td>OBC</td>
<td>Street vendor</td>
<td>100000</td>
</tr>
<tr>
<td>4</td>
<td>*Snehal Suhas Deshpande</td>
<td>15</td>
<td>F</td>
<td>60-65</td>
<td>Brahmin</td>
<td>Computer Institute</td>
<td>800000</td>
</tr>
</tbody>
</table>
The profile of teachers/ supervisors who are the respondents of study is as follows,

**Table 1.4: Profile of Interviewed Teachers of Mentally Challenged Children**

<table>
<thead>
<tr>
<th>Sr. No</th>
<th>Name of Teacher/Supervisor</th>
<th>Sex</th>
<th>Age</th>
<th>Qualification</th>
<th>Caste</th>
<th>Years of experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>*Sneha Vinay Sahashrabuddhe</td>
<td>F</td>
<td>42</td>
<td>PhD in Home Science</td>
<td>Brahmin</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>*Madhura Mohan Bhat</td>
<td>F</td>
<td>45</td>
<td>B.A in Psychology</td>
<td>Brahmin</td>
<td>15</td>
</tr>
<tr>
<td>3</td>
<td>*Kishor Rambhau Madake</td>
<td>M</td>
<td>38</td>
<td>Mechanical Engineer</td>
<td>Maratha</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>*Sanjay Sinha-Yadav</td>
<td>M</td>
<td>40</td>
<td>Master in Social Work</td>
<td>Brahmin</td>
<td>13</td>
</tr>
</tbody>
</table>

(*The original names have been changed for the confidentiality*)

**1.4.5.5 Data Interpretation and Analysis:**

I followed following three steps for data analysis.

a) Development of Transcripts

b) Case Narration
c) Cross Case Analysis

The details of the interview were recorded and developed verbatim transcripts for each interview. The transcripts were translated from Marathi to English after each interview. Case narrations were further developed from the transcripts. The cases were analyzed individually. A Cross case analysis method was used to analyze the cases. The researcher captured the theme or pattern prominent in cases based on the concern and subject of the study. The unique themes or patterns arising helped to develop insight in the study.

1.4.6 Limitations of the Study:

Though current study extensively focuses on the aspirations of the mentally challenged children and response of non-mentally challenged towards them, however, the study has following limitations.

a) Confined to mentally challenged children from moderate and mild category:

Though non participant observations is made in school with all type of children, for the study mentally challenged children (mild and moderate category-whose IQ is in between 35-70) are interviewed. Mentally challenged children from severe and profound category (less than IQ 35) are not selected for study due to limitations in the interactions with these children.

b) Limited area of study: Through the teachers from two special schools are interviewed, all the six cases are covered from one special school in Pune city.
Chapter II

Survey of Literature
(Society and State’s Response to Mental Retardation)

This chapter discusses the available literature on the research theme and discuss it in Indian context. It broadly discuss the concept, degrees, myths and misconceptions about mental retardation, and focuses on the history of discrimination to mentally challenged children and end with the discussing the major policies and institutions formed for the betterment of mentally challenged people.

2.1 THE CONCEPT OF MENTAL RETARDATION

Mental Retardation is a condition in which there is delay or deficiency in all aspects of development, i.e. there is global and noticeable deficiency in the development of motor, cognitive, social, and language functions. The National Trust Act-1999 describes mental retardation as ‘a condition of arrested or incomplete development of mind of person, which is specially characterized by sub-normality of intelligence’.

Mental retardation is the commonest form of developmental disability. In many ways, mental retardation is also representative of developmental disabilities in general, in its causation, nature, and care. As noted earlier, mental retardation is a condition in which there is a significantly sub-average mental development from birth or early childhood. Most people with mental retardation have the condition from birth. In a small number, the condition may occur following damage to the brain in later childhood. This could, for example, follow an episode of brain fever.

Mental retardation is also termed as mental deficiency, mental sub-normality, and intellectual deficiency. Generally, mental retardation is a life-long condition (Health and Human Right: A Resource Guide). Those affected continue to have diminished intellectual capacity throughout their lives. However, in most individuals with mental
retardation, those parts of the brain that are not damaged continue to develop. Therefore, they continue to acquire skills and abilities as they grow older, even if slowly.

Most importantly, we must keep in mind that mental retardation is not mental illness. Report on World Mental Health day-2008: By Shrimati Motibai Thackersey Institute of Research in the Field of Mental Retardation discuss on confusion over terms of mental illness and mental retardation. Mental Disorder affects nearly 12 percent of the world’s population. Mental illness and mental retardation are two such disorders which are often in a state of confusion. The two disorders were clubbed together under the lunacy act 1912 and still the same confusion prevails in our society today, in spite of the fact that the Mental Health Act (1957) segregated them. The major characteristic of mental retardation is delay in mental development, whereas the major characteristic of mental illness is disturbance in the mental functions of thinking, feeling, and behaviour. Mental illness can occur at any age, whereas mental retardation is present from childhood. However, some people with mental retardation may also develop mental illness.

Naturally, mentally challenged babies fail to develop and acquire milestones like non-mentally challenged children. These conditions, in which there is a significant deficit or delay in the development of various mental functions from early childhood, are called developmental disabilities. One can recognize different types of developmental disabilities, depending on what function or functions are affected and how extensive is the limitation.

2.2 Degrees of Mental Retardation

Not all people with mental retardation have the same level of intelligence. The scientific method of measuring intelligence is through standardized psychological tests called IQ tests. IQ or intelligence quotient is the percentage of intelligence a person has, in comparison to a normal person from a similar background. An IQ of 100 is considered normal intelligence. The lesser the IQ, the more severe is the level of mental retardation. Based on IQ, mental retardation can be classified into different degrees as follows:
Figure 2.1: IQ-wise distribution of Mentally Challenged Population

As shown in Figure 2.1, the most of (85%) mentally retarded people are mildly retarded with having IQ level 50-70\(^4\) and 10 percent population of mentally retarded people fall into moderate category with having IQ in between 35-49. However, very few mentally retarded people around (5%) from mentally retarded suffer from severe and profound retardation with below 35 IQ.

2.3 Functioning and Development of People with Mental Retardation

A more practical and simpler way of classifying mental retardation is to think of only two categories: mild mental retardation with an IQ range of 50-70, and severe mental retardation with an IQ below 35. Though the concept of IQ is useful in some ways, it does not always give the true picture of the abilities of the person. A related and more appropriate measure is the social quotient (SQ) (Baquer Ali and Anjali Sharma 1996), in which importance is given to the acquisition of socially relevant skills.

Table 2.1 illustrates the attainments of people with different degrees of mental retardation. It is clear that even those with severe mental retardation can become at least

\(^4\) People above IQ 70 up to 84 are considered as having borderline intellectual functioning
partly independent in looking after themselves through proper supervision, care and training.

Table 2.1: Adult Attainments in different degrees of Mental Retardation

<table>
<thead>
<tr>
<th>Degree</th>
<th>IQ range</th>
<th>Adult attainments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>50-70</td>
<td>Literacy +</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-help skills++</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Good speech ++</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Semi-skilled work +</td>
</tr>
<tr>
<td>Moderate</td>
<td>35-50</td>
<td>Literacy +/-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-help skills +</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Domestic speech+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unskilled work with or without supervision +</td>
</tr>
<tr>
<td>Severe</td>
<td>20-35</td>
<td>Assisted self-help skills+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Minimum speech+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assisted household chores +</td>
</tr>
<tr>
<td>Profound</td>
<td>Less than 20</td>
<td>Speech +/-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-help skills +/-</td>
</tr>
</tbody>
</table>

Note: + means attainable; ++ means definitely attainable; +/- means sometimes attainable

(Source: World Health Organization website available at,  
http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1825_8090.htm)
2.4 Myths and Misconceptions about Mental Retardation

Despite the changing perceptions, many myths and misconceptions about mental retardation persist among large sections of the population in countries of the region. These myths need to clarify with scientific information through popular media.

a) Myth: Mental retardation is a hereditary problem.
Fact: Only a few causes of mental retardation are hereditary, i.e. passed on from parents to children. Mental retardation is often caused by external influences, some of which can be prevented.

b) Myth: Bad deeds in the previous life of parents cause mental retardation.
Fact: This is completely false. Such beliefs add to the suffering of the families who are already overburdened with caring for their mentally challenged children. Some communities perpetuate the myth that if one tries to remedy the illness or take treatment, the suffering will be repeated in one's next life. This results in added suffering to the patient from lack of proper treatment.

c) Myth: Mental retardation is caused by pregnant and lactating women not following restrictions on food.
Fact: Pregnant and lactating women must maintain good nutrition for their own health and also for the health of the unborn or newly-born child. There is absolutely no basis for restricting food to pregnant and lactating women. However, some medications, if taken during pregnancy, may lead to malformations in the unborn child. Medication should be taken only on the prescription of a doctor. When consulting a doctor for an illness, women should always inform the doctor about being pregnant.

d) Myth: Mental retardation is infectious.
Fact: This is completely false. Mental retardation cannot be spread by touching a patient (Dr. Satish Girimaji and et al, 2001). Children with mental retardation must be cuddled and loved just as much as non-mentally challenged healthy children.

e) Myth: Tonics/vitamins/medicines can cure mental retardation.
Fact: If mental retardation is caused by a treatable condition, appropriate treatment will cure it. However, there are no "brain tonics" which can stimulate a damaged brain. Many unscrupulous healers and manufacturers market such substances with popular and misleading names, which imply that if these substances are taken, the child will become normal. This is particularly common in rural areas, where quacks market some mixtures, guaranteeing parents a cure. These substances frequently contain a substance called ‘steroids’. These medications make the child plumper and perhaps happier temporarily, which makes the parents feel good. But the basic condition of mental retardation is not cured. In fact, steroids are harmful if taken for long durations.

f) Myth: Brain operations can cure mental retardation.
Fact: There are very few conditions leading to mental retardation which can be cured by surgery.

g) Myth: Marriage can cure mental retardation.
Fact: This is completely false. In fact, a mentally retarded person should be married only with the full consent and knowledge of the partner.

h) Myth: Children with mental retardation become completely normal when they grow up to be adults.
Fact: Children can make substantial progress as they grow up. However, it is unlikely that they will become completely normal. Each case must be assessed individually.

i) Myth: Mentally retarded adults have poor sexual control and pose a danger to others.
Fact: In fact, mentally challenged adults are sexually more inhibited than their non-mentally challenged counterparts. On the contrary, many such people are victims of sexual abuse.

j) Myth: Mentally retarded children are incapable of learning anything and so everything has to be done for them.
Fact: These children are capable of learning, although how much they learn and at what speed they learn may vary. The harder we work with them, the more they will learn and more independent they can become. There is no better solution to their development than working hard with them.

k) Myth: Mentally retarded children should not be made to cry for any reason or should not be disciplined in any fashion.

Fact: All children need to be disciplined. Every effort should be made to teach children with mental retardation what is right and what is wrong, recognizing their capacity for learning and taking into consideration factors beyond their control.

l) Myth: Faith healers can cure mental retardation.

Fact: This is completely untrue. There are many sad stories about parents selling all their valuables and their land on the advice of faith healers and giving this away in charity, frequently to the faith healer. Faith healers mislead the parents.

2.5 CAUSES OF MENTAL RETARDATION

Why does mental retardation occur? As noted earlier, anything that damages and interferes with the growth and maturation of the brain can lead to mental retardation. There can be hundreds of such causes. This might happen before, during or after the birth of the child. While a few examples are explained below, a more detailed list of causes is given in Table 2.3

<table>
<thead>
<tr>
<th>Category</th>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prenatal (causes before birth)</td>
<td>Chromosomal disorders</td>
<td>Down’s syndrome*, Fragile X syndrome, Prader Wili syndrome, Klinefelters syndrome</td>
</tr>
<tr>
<td>Single gene disorders</td>
<td>Inborn errors of metabolism, such as galactosemia*, phenylketonuria*, mucopolysaccaridoses, Hypothyroidism*, Tay-Sachs disease, Neuro-cutaneous syndromes such as tuberous sclerosis, and neurofibromatosis, Brain malformations such as genetic microcephaly, hydrocephalus and myelo-meningocele*, Other dysmorphic syndromes, such as Laurence-Moon Biedl syndrome</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Other conditions of genetic origin</td>
<td>Rubinstein Tabi syndrome De Lange syndrome</td>
<td></td>
</tr>
<tr>
<td>Adverse material / environmental influences</td>
<td>Deficiencies*, such as iodine deficiency and folic acid deficiency, Severe malnutrition* in pregnancy, Using substances * such as alcohol (maternal alcohol syndrome), nicotine, and cocaine during early pregnancy, Exposure* to other harmful chemicals such as pollutants, heavy metals, abortifacients, and harmful medications such as thalidomide, phenytoin and warfarin sodium in early pregnancy, Maternal infections such as rubella*, syphilis*, toxoplasmosis, cytomegalovirus and HIV Others such as excessive exposure to radiation*, and Rh incompatibility*</td>
<td></td>
</tr>
<tr>
<td>Perinatal (around the time of birth)</td>
<td>Complications of pregnancy*, Diseases* in mother such as heart and kidney disease and diabetes, Placental dysfunction</td>
<td></td>
</tr>
<tr>
<td>Labour (during delivery)</td>
<td>Severe prematurity, very low birth weight, birth asphyxia, Difficult and/or complicated delivery*, Birth trauma*</td>
<td></td>
</tr>
<tr>
<td>Neonatal (first four weeks of life)</td>
<td>Septicemia, severe jaundice*, hypoglycemia</td>
<td></td>
</tr>
</tbody>
</table>
| Postnatal (in infancy and childhood) | Brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis  
| | Head injury*  
| | Chronic lead exposure*  
| | Severe and prolonged malnutrition*  
| | Gross understimulation* |

Note: conditions marked with an asterisk (*) are definitely or potentially preventable.

(Source: Word Health Organization website available at,  
http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1825_8090.htm)

2.5.1 SOME COMMON CAUSES OF MENTAL RETARDATION

Here we discuss few common causes of mental retardation, which cause mostly for the mental retardation

2.5.1 Down’s Syndrome: The human body is made up of billions of cells. Each cell contains 46 thread-like structures called chromosomes. In Down’s syndrome, because of a biological error around the time of conception, the cells come to have one extra chromosome i.e, 47 instead of 46 chromosomes. The presence of an extra chromosome in the cells interferes with the normal development of the brain, leading to mental retardation (Anna Kessling & Mary Sawtell 2000). Down’s syndrome is a common cause of mental retardation. It is often possible to recognize people with Down’s syndrome by their facial appearance, characterized by up-slanting eyes and flat bridge of the nose. Down’s syndrome occurs in about 1 in 800 newborn babies (Anna Kessling & Mary Sawtell 2000). Even though it is a genetic disorder, Down’s syndrome is most often not inherited and can occur in any child. However, it is more likely to occur when the age of the mother at the time of the birth of the child is over 35 years. Even though persons with Down’s syndrome have mental retardation, they possess good social and interactional skills.

2.5.2 Inherited Metabolic Disorders: Chromosomes in the human cells contain genes which control growth and maturation of the brain. Some of these are responsible for
chemical (metabolic) reactions, which are essential for brain growth. If such a gene is abnormal, it can lead to derangement of metabolic reactions and thereby cause mental retardation. Phenylketonuria is one such condition (National Institute of Child Health and Child Human Development 2010). Babies with phenylketonuria, in addition to mental retardation, have light-coloured hair and skin, a small head, and are prone to convulsions.

### 2.5.3 Maternal Rubella Syndrome:
Rubella or German measles is generally a harmless viral infection in adults, producing symptoms of mild fever, rash, and enlargement of lymph nodes. But when it occurs for the first time during early pregnancy, the virus spreads to the baby growing in the mother's womb and causes extensive damage. When such a baby is born, it is likely to have mental retardation and visual impairment.

### 2.5.4 Iodine Deficiency Disorder (cretinism):
Iodine is essential for the normal development of unborn babies. Lack of adequate availability of iodine from the mother restricts the growth of the brain of the foetus, and leads to a condition called hypothyroidism (George S. Baraff with Gregory Olley 1999). Babies with this problem have mental retardation, hearing impairment and dwarfism. In addition, they may have lethargy, coarseness of facial features, rough and dry skin, feeding problems, constipation, cold extremities, and neck swelling because of enlargement of the thyroid gland. A severe form of this condition, in which all the features mentioned are very pronounced, is called cretinism.

Iodine occurs naturally in food. But in some places, the soil and the food are deficient in iodine. In such places, naturally, a pregnant woman's intake of iodine is less and therefore their infants would also be deficient in iodine and manifest hypothyroidism.

### 2.5.5 Difficult/Complicated Delivery:
Till babies are born, they receive their supply of food and oxygen from the mother. Immediately after birth, babies begin to breathe on their own. Normally, this transition occurs smoothly. When, for any reason, the delivery becomes difficult, prolonged, or complicated, oxygen supply to the baby is diminished. As the brain is very sensitive to oxygen deprivation, this can result in brain damage. This
is called birth asphyxia. Such babies may have problems in development such as mental retardation or cerebral palsy.

2.5.6 Brain Infection (Brain Fever): An important cause of mental retardation after birth is brain infections caused by bacteria or viruses. In this condition, children who are otherwise normal, suddenly develop fever, headache, vomiting, convulsions and loss of consciousness. If this infection is severe, there may be irreversible brain damage leading to mental retardation. Such children, when they recover from acute illness, are noticed to have lost many skills which they had learnt earlier. Young children are more at risk for brain fever in regions where Japanese encephalitis and tuberculosis are common.

2.5.7 Nutrition and Mental Development: A balanced diet rich in calories, protein, vitamins and minerals is required for pregnant women and young children for normal brain development. Lack of adequate diet can have direct and indirect effects on brain development and thereby increase the risk of subnormal development. Studies have shown that birth weight is an important indicator of the future health of the baby. A baby with low birth weight is more likely to have problems in mental development. The height and weight of would-be mothers and the extent of weight gain in pregnancy are important factors determining birth weight.

2.6 Common Health Problems Associated with Mental Retardation

Many children and adults with mental retardation are otherwise physically and mentally healthy, except that they have lower intelligence. Several others, however, frequently have other problems. The common health problems associated with mental retardation are as follows

2.6.1 Behaviour Problems: Symptoms like restlessness (continuously moving around; unable to sit in one place), poor concentration, impulsiveness, temper tantrums, irritability and crying are common. Other disturbing behaviour, like aggression, self injurious behaviour (such as head banging) and repetitive rocking may also be seen. When such behaviour is severe and persistent, it can become a major source of stress for
families. Therefore, attention should be paid to reduce such behaviour while providing treatment and care.

2.6.2 **Convulsions:** About 25 percent of people with mental retardation get convulsions. Many types of convulsions can occur involving the whole body, or only one half of the body, or sudden single jerks leading to a fall. Convulsions, although alarming to watch, can be easily controlled with proper medication.

2.6.3 **Sensory impairments:** Difficulties in seeing and hearing are present in about 5-10 percent of persons with mental retardation. Sometimes these problems can be resolved by using hearing aids or glasses, or undergoing surgery for cataract. As noted earlier, other developmental disabilities, such as cerebral palsy, speech problems and autism can occur along with mental retardation. Persons with many disabilities, or multiple disabilities, pose a big challenge in terms of providing care and facing society.

2.7 **History of Neglect and Discrimination**

In all countries of the world, people with disabilities and particularly mentally challenged people are the largest minority group. As a group they are starved of services and facilities available to the non-mentally challenged people and, consequently, are the least nourished, the least healthy, the least educated, the least employed. They are subjected to a long history of neglect, isolation, segregation, poverty, deprivation, charity and even pity.

The plight of the disabled in India is not dramatically different. The immense responsibility for the care of the disabled is generally left to their families and a few institutions managed by voluntary organisations and government. Since the mentally challenged people, as yet, do not have any economic or political or media power in India, they tend to be mostly ignored by society.

These common practices reinforce the traditional and misguided stereotypes that continue to project mentally challenged people with disabilities as deserving pity, alms and charity. The prejudices against the mentally challenged people and ignorance about their
potential get institutionalised and are inevitably reflected in policy making, resource allocation, service provision and the status accorded to them.

2.8 AVAILABLE GOVERNMENT SCHEMES AND POLICIES FOR MENTALLY CHALLENGED CHILDREN

India, being welfare state have initiated and designed various policies and schemes for welfare of the disabled people, including mentally challenged people. Here we discuss few important government policies and schemes available for mentally challenged people.

2.8.1 Persons with Disabilities Act 1995: The Constitution of India ensures equality, freedom, justice and dignity of all individuals and implicitly mandates an inclusive society for all including persons with disabilities. In India, the National Policy for Mentally Handicapped, first of its kind was formulated in 1988, which gave an impetus to the development of Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995. Coming into force in 1995, this Act envisages mandatory support for the prevention, early detection, education, employment and other facilities and social security benefits for the welfare of persons with disabilities in general and mental retardation in particular. In addition, this Act provides for affirmative action and non-discrimination of persons with disabilities. In keeping with this Act, several states in India have begun providing many social security measures like disability pension, family pension, scholarships for special education, travel concession, income tax relief and special insurance policies. This Act treats disability as a civil rights rather than a health and welfare issue (Disability India Network). The Law recognises that the primary issue facing disabled people is their exclusion from the mainstream activities of the society and hence the emphasis in the Law is on full integration and participation. It is discrimination, and not impairment, that disables people. The Law recognises the importance of consultation with disabled people on issues which directly or indirectly affect them.
2.8.2 National Trust Act 1999: Another positive development in India is the promulgation of the National Trust Act in 1999. The spirit behind this Act is to actively involve the parents of mentally challenged persons and voluntary organizations in setting up and running a variety of services and facilities with government funding. It is hoped that the implementation of this Act will be the answer to an important concern of parents, viz., “what will happen to our child after we are no more”.

2.8.3 National Institute for the Mentally Handicapped (NIMH): NIMH was established as an apex body in the field of mental retardation by the Government of India in 1984 at Secunderabad in Andhra Pradesh. The main objectives were to develop human resources, models of care and rehabilitation, and to undertake research, documentation, and information in the field of mental retardation. Since its inception, NIMH has grown by leaps and bounds, with many achievements to its credit and a visible impact on the national scene. Its major contributions have been manpower development, numerous and very popular publications on early stimulation, education, training, and rehabilitation. The Institute has been able to develop innovative models of family and community-based care that have undergone research evaluation, and has functioned as a clearing house of information at the national level. Recently, it has been instrumental in promoting and supporting the parental self-help group movement in India. Other notable activities include an annual national seminar on mental retardation, an annual meet of parent organizations, Special Olympics, awareness campaigns and a national meet of special employees. (Ali Baquer and Anjali Sharma)

The Institute has many regional centres all over India, mainly to run training courses for manpower development.
Chapter III
Discussion- The Field Realities

Aspiration and Childhood of Mentally Challenged Children and response of Normal Childhood

Having the detailed discussion on design of the study and available literature on the research concerns, here I start the discussion on the data analysis and the field realities of the study. The analysis of study is divided into two chapters. In this chapter, I start with the discussion on the aspirations of the mentally challenged children in aspect of their likes, dislikes, and their general perception about future (carrier or goal), in later part discus how non-mentally challenged children perceive and respond to the mentally challenged children.

3.1 Likes, Dislikes and Future Aspirations of the Mentally Challenged Children

Psychological concepts such as imagination, aspiration and conceptualization are very much related to the childhood. In general all children in their childhood imagine and try to conceptualize their future in life. Surrounding environment of family and community atmosphere plays the significant role in the imaginations of the children. Here, I tried to understand mentally challenged children’s likes, dislikes, and imagination of carrier aspirations.

We experience life with our senses—eyes, nose, tongue, ears, tactile sensory organs, etc. Our perception is further enriched by our limbs like hands and legs. We come to know what is distant and what is near when we move. The sense of touch is most effectively felt and conveyed by our palm and fingers. A potter imprints her own experiences of touch through the texture of her fingers in a pot. We experience this sense of touch when we hold it in our hands. We live our life through the sense cues. The sense cues are the ‘hints’ our senses constantly receive in any space to recognize what it is like and what is
happening in it. Our brain processes this information and orders other senses and organs to sensitively respond to it.

If our eyes ‘see’ stairs, we (along with our legs and hands) become careful of the level differences and look for the rails and supports. When our ears hear the sound of a car horn while crossing the roads, our legs immediately stop to avoid any accident. We continuously take cues from our surroundings and respond to it. Be it for bare functional needs of just walking, eating or sitting, or for an aesthetic appreciation of a scenic view, a piece of music or a garden of fragrant flowers, these cues is an essential part of our daily life.

These sensory cues are just supports for us – to live and experience life, they themselves are not experience, but they let you feel what is to be experienced. They make us aware of the environment we live in. They are perceived through our sensory organs. But what would happen to a person whose either sensory organs or limbs, for some reason, are not functioning at its best or have some type of mental and/or physical impairment?

Mentally challenged children are individuals with their own, identities, aspiration, personalities and points of views. They have wide range of interests, hobbies, skills and potentials abilities. They have their moods and capacity to laugh, enjoy, a joke, hum a song. They have their own lifestyles and their own dreams. If some of them cannot walk on the beach, still they admire the waves. If someone of them is unable to see, they still have the sense of touch, taste, smell and hearing. If they miss on one faculty, they compensate it with others (it’s commonly believed that it’s not naturally but they work hard and build it.). They too enjoy tasty foods, fashionable cloths, privacy, friendship, and travel without hurdles.

Generally mentally challenged children from severe and profound retardation category do not express their aspirations and future, but it’s very difficult to say that they don’t think in this direction. At the same time children from moderate and mild are much particular about their likes and dislikes. Children from moderate category shared that they want to
do some sort of jobs to earn money. These children even talked about jobs, their marriages and own homes.

Like the normal girls, mentally challenged girl also like to do make-up and look like heroines, whereas boys have their own favourite heroes and cricketers. These boys like to imitate and follow their style. One common hobby irrespective of gender among these children is watching TV. Most of children spend their almost time in watching various serials and movies on TV at home.

Out of six cases of the study, five children very openly shared their interest, likes and dislikes and also very vaguely talked about their future plans.

Rajendra is 16 year old, having IQ in between 45-50. He lives with his parents and elder sister in the community. Rajendra has interest and like to play musical instruments. He is much interested in learning *Tabla*¹ and is much optimistic that he will be good *Tabla* player one day in future. Hapij has interest in the games such as cricket. Hapij is 14 year’s boy from moderate category of mental retardation and after his school he helps his mother for delivering dinner-dabbas to neighbouring college students, as her mother run a small mess at home. Hapij like to dance and in his school’s many cultural programmes he participated, he has also won the special award for dance performance at city level arranged for mentally challenged children. He shared his deep interest in developing his skills in dance. Namdeo, 17 years old boy of the street vendor has IQ in between 35-40. Namdeo has much interest in painting, he also showed me his few beautiful paintings and shared that his school also promote his interest. But he is unhappy because he doesn’t get free time at home as he has to help his parents to clean and rearrange the vegetables for the next day to sell.

Snehal is 15 years and have IQ in between 60-65. It is very difficult to the stranger to identify Snehal as mentally challenged girl, because she manages herself very well. Her father run the Computer Institute, he purposefully taught basic operating and handling of computer to Snehal. So Snehal, after school most of time spend on computer. Her father

¹ *Tabla* is Classical Indian musical instrument having two drums.
shared that, Snehal help for simple data entry work, even once she helped for data entry to her cousin, who stays in U.S. The only problem with Snehal is her typing and data entering speed is very slow, but she does this work with great interest. Her family is in support for her marriage also. Her parent shared that if somebody agree and accept her with her condition, they will like to see her married life.

Chhaya is the only child of a cloth-shop owner having IQ in between 50-55. Chhaya is 13 year old now and enjoy her presence in her special school. Chhaya has a lot interest in new and fashionable cloths, eating outside and shopping. She likes to use costly cosmetics and make-up. As she is the only child of economically well settled family, they try to fulfil all the demands of Chhaya, and her mother occasionally use to take her for shopping. As her present special school allow children till the age of 18 years, her parents are not much concerned about her immediate future. Meera, 15 year old girl having IQ in between 35-40 is little shy and non-expressive. Her father is forth class worker in the city’s municipal corporation, and mother is domestic worker. Her younger brother is normal and studying in high school. Meera like to go outside in market and just for walk, but as everyone (parents) is much engaged in their work, Meera very rarely get opportunity for moving out of home except her school. Most of time she watch TV at home, she like dance programs and movies with fighting to watch on TV.

3.2 SPACES AND OPPORTUNITIES TO BE OPEN AND SHARE AND FRIENDSHIP PATTERN

Generally, mental challenged children are very close to their father and share joy, happiness, disinterests with him, but for hygiene and menstrual level girls children share it with mothers. But it was observed that very rarely mentally challenged children share with their close siblings.

Non-mentally challenged children with whom I conducted focused group discussions, none of them had formal or informal friendship with mentally challenged children. At least six children shared that in their or in neighbour building/block mentally challenged children reside. Out of them one girl’s cousin live at her neighbour so she had some type of relation and one boy tried to establish friendship with mentally challenged children but
this relation was not welcomed by their families. This picture is also supported by the focus group discussions with mentally challenged children, in which no challenged children shared his/her friendship with non-mentally challenged children. But interestingly mentally challenged children have very good friendship within themselves and many children shared the names of their friends in their special school.

![Picture 1: Mentally Challenged girls spending interval time](image)

Picture 1: Mentally Challenged girls spending interval time
3.3 Normal Childhood’s Response to Mentally Challenged

Understanding the perceptions and views of the non-mentally challenged children about mentally challenged children and their childhood is one of the key research concerns of the study.

I conducted two Focused Group Discussions with mixed group of 10th class with Marathi medium, where generally students were from low-medium income groups. First of all at the starting of FGD, I conducted a simple exercise with participants. To explore what they think and what they know about the challenged children, I told them to write at least five lines on these issues on given paper. Here I am explaining the content analysis of the writings from high school students about challenged children of this exercise.

First of all normal children do not know much about challenged children. The common misunderstanding among these children is either they are Vede or with low intelligence. Non-mentally challenged children used words to mentally challenged children as Vede,
**kami akkaleche** (with low intelligence, foolish, unwise). Even two children described them as dirty children ‘Ghanerade’.

Interestingly two children wrote that, only those parents deliver challenged children who are suffering from retardation related problems. One boy described that at his neighbour a family having such children lives. Sometime this mentally challenged boy come at society’s playing ground to play with normal children but children avoid him in a cricket team. So he always silently watches the match. Interestingly two children related condition of mentally challenged children to the bad deeds done by them in earlier birth. I further tried to discuss on this remark in the discussion on focussing on these two students. These students shared that they came to know from their families that our next birth depend on the virtue and goodness done by us in this birth, so the mentally challenged children might have this condition due to their sins in earlier birth. I was shocked by these firm responses by these high school students. Their responses are very close to the doctrine of KARMA which has guided thinking and practice of all Hindus for centuries. The theory of karma explains the impairment of an individual as of retribution of sins committed by her/him in previous life. In both FGDs only three students shared that mental retardation come by birth only, and do not occur after the birth. Other students were silent on this issue, because they shared that they do not know much about the reasons of mental retardations.

### 3.3.1 The Sources of Information about Mental Retardation

Whatever these non-mentally challenged children know about mentally challenged children; get to know from the discussions with peers and their family. No student shared that he/she has ‘read’ about challenged children in newspaper/school books or other reading sources. Whatever they know is either ‘heard’ from somewhere or seen on television and movies. Even after my purposeful question about having any programme or class or lecture attended by them during their school life, no children replied positively. They did not attend and had any such type of programme on the issues of mentally challenged children and mental retardation. When a student shared that he recall mentally challenged children from the hindi movie ‘Tare Jamin Par’, other students also
added to it and said that they have also seen the movie. They also added that it is shown in movie that Ishaan, the mentally challenged child who is not able to concentrate on his study, is not able to get good friends and he prefers loneliness. In his family only his mother loves him and his father and brother always hate and dislike him. The life of Ishaan suddenly change when Amir khan, the teacher notice him.

It clearly shows that discussions with and in family and television programs and movies are the major source for the non-mentally challenged children to know about the challenged children. These sources are not passing the right and scientific information to the receivers.

3.3.2 Perceptions and Experience about Mentally Challenged Children

Five non-mentally challenged children in FGD shared that there have mentally challenged children in their neighbourhood.

1) Sangita is studying in 10\textsuperscript{th} class and her 15 year old cousin Vaishali is mentally challenged. Sangita shared that Vaishali can manage herself very well, she do sweeping, cleaning the flours, arranging beds, washing clothes and utensils. But her mother never taught her the cooking; even she is not allowed to make the tea. She very rarely gets the opportunity to come out of the home. Sangita and Vaishali are of the same age and close relatives and her parents also do not restrict her to interact with Vaishali, so they have fare friendly relations.

2) Mohan, 13 years old mentally challenged boy lives at Sanjay’s neighbour. Mohan travels independently by bus and goes to special school. Sanjay has no peer of his age in his building without Mohan. So he was using to go at Mohan’s home to have chat and play infrequently. Even Mohan was also coming to Sanjay’s place. They both were having good relation. Sanjay shared once their family Guruji (guru) visited their home. They discussed and advised to Sanjay’s parents that Sanjay should be keep in ‘good atmosphere and in company’ of good friends for academic development. From that time parents stopped Sanjay’s interaction with Mohan and suggested to have good friends from neighbouring building. Sanjay further shared, after this incidence once he interacted
to Mohan on the way so his mother threatened him and warned to tell his father if he meet again to Mohan.

Almost Participant children told they don’t like the friendship with mentally challenged children. Only one girl whose cousin is mentally challenged expressed her interest in friendship with her. The common reason shared by children was the logic which they learned that if they want to be ‘well developed’ them need good company “Changlya lokat rahunch vikas hoto”. When I explored more that from where they learnt about this, children shared that it is general, in our school and family we are always taught that we should always keep ‘good company’- “Changalya lokanchi sangat karavi”. Two students said that they were interested in friendship with challenged friend but their parents and family were not happy with their interaction and friendship and forced them to stop these relations.

Another significant reason reported that if non-mentally challenged children make friendship with challenged children, they fear that people will tease them and call them friend of stupid (veda), so to avoid such teasing from society they don’t prefer friendship with mentally challenged children. A girl whose cousin is mentally challenged shared that whenever she goes in market or some public places, the people steer to them and discuss about them. She explained that due to these experiences of embarrassment she avoid to take her cousin at public places. One more reason normal children shared that there is constraint of choices and limitation of interest. Mentally challenged children can’t play the games with us as per requirement of games so for full enjoyment so they prefer the non-mentally challenged friends to fully enjoy the games “Amhala tyanchy peksha itar mitranbarobar khelayala avadate.”

I conclude this chapter with summarising that, mentally challenged children do express and have their interest, like and dislikes and have good friendship within themselves, but non-mentally challenged children due to their own misunderstanding, family and society pressure avoid their friendship.
Chapter IV

Experiences of Discrimination in Family and Society

In this chapter, I discuss how and what type of problems, pains, discrimination and isolation mentally challenged children face in their own family and society including public places, neighbours, relatives and special school. I think, it will be unjust to starting discussion on the discrimination of these children in their families, because many ways as whole family also suffer in society because of having mentally challenged children at home. Therefore, I start this chapter with family related issues of mentally challenged and then discuss their discrimination in the family and society on various aspects.

4.1 Mentally Challenged Child and Family

There is a lot of truth in statement that ‘the birth of disabled child makes the entire family disabled’. The families with mentally challenged children face enormous difficulties in looking after their mentally challenged members and most of time the support that they provide to these children goes unrecognized by society. Besides medical, health, and social services, the members of the family need at times counselling and hand-holdings so that they can continue with the uphill task put on them.

A majority of mentally challenged children are born with mental retardation or acquire it in their early years. The parents and other members of the family realize that something has gone wrong but either find it difficult to express their concerns or ask the right questions to people who do not know. I interviewed total six parents and out of them three reported the downs syndrome as the cause of the children’s mental retardation. In two cases children suffered from it after the normal birth, whereas in one case it happened due to the critical delivery. Education and economic status of parents, both matter in the caring and acceptance of mentally challenged children but the parent’s education status matter more compare to economic status, because in educated parents acceptability of challenged children as special child is high and they know how to handle and deal with child.
In most cases the news about their child’s mental retardation is broken them in most unsympathetic manner. They run from one doctor to another and from one specialist to next without any precise understanding of their child’s problem. Apart from feeling of frustration, guilt and despair, important opportunities for helps are lost and permanent damage sets in. The following case of Snehal’s family clearly depicts that how the whole family is suffering due to her condition.

Mr. and Mrs. Deshpande shared that it was normal delivery at home when Snehal did born, everyone was happy in family because baby cried after two minutes and was looking very normal. But after one month also she was not moving her limbs frequently and was suffering from breathing-problem (she was breathing loudly), so few old neighbouring women suggested that body massage was required for baby, so they did it for next one month. But there was no improvement. After three month she got fever and so she was admitted to hospital. She was hospitalized for 10 days and then doctor referred to another child specialist where she was diagnosed as the case of mental retardation. Mr. and Mrs. Deshpande shared that it was really mental shock for them, because this was their second girl child, and relatives started to blame them that, this happened because of they shifted from village to Pune city despite of family’s willingness, Mr. and Mrs. Deshpande had such baby. So due to this tension they did not perform any religious ritual of small baby. After the detailed diagnosis it was found that the reason behind Snehal’s mental retardation was Down’s syndrome.

As the Snehal’s elder sister is normal, Mr. and Mrs. Deshpande took decision for third baby in hope of boy child. At time of this third pregnancy after Snehal, doctor warned that there is rare possibility of another same baby, so fetus was checked and was identified as normal. So it was normal delivery with normal baby boy. Mr. and Mrs. Deshpande shared that at time of this third pregnancy they went through tremendous mental pressure, because relatives and neighbours were whispering that this third baby will also be mentally retarded. Muscles

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6 In general there is widespread understanding in people that body massage to babies helps their muscles and bones to be more stronger
Now Snehal is 15 years old and Ankita her elders sister 21. Ankita completed her master in computer Science and now working in BPO with good salary. Mr. Deshpande started searching mate for Ankita from last year. In between four families liked her photo and bio-data and were ready to on marriage proposal. But, unfortunately whenever Mr. and Mrs. Deshpande shared about Snehal with them or when they came to know about Snehal, these families rejected Ankita’s marriage proposal by giving other reasons. Mr. and Mrs. Deshpande are deeply disappointed with these experiences but they think that to share about Snehal to these families was very important to avoid further complications in relations. Mr. and Mrs. Deshpande hope that very soon they will find a person for Ankita who accept Snehal’s condition.

4.1.1 Family Stress and Adaptation

Families face a lot of stress and difficulties while caring mentally retarded children in family. They encounter different problems at different stages. Stress may take many forms such as demands of daily care, lack of leisure time, emotional disturbances such as worries, frustrations, sadness, irritability, and relationship problems between family members. In addition, there is stigmatization, social embarrassment, and financial implications.

4.1.2 Pressure of Daily Cares:

Mrs. Madhura Bhat, the special teacher for mentally challenged children is working with mentally challenged children since last 15 years. Mrs. Bhat is also engaged in school’s parent counselling centre. She shared a case which she is handling since last few months. Dipak is 14 years old and is IQ ranges in between 35-40; he is also suffering from autism. Dipak live with his parents and elder brother. Both his father and elder brothers are employed. Mother is the only person who takes care of him at home after and before school. From previous few months, his mother started problem of mental stress and one psychologist suggested her for Yoga for mental stability. Now the problem is that the timing of her Yoga class is 7 am to 8.30 am, and Dipak’s father and elder brother leave at 8.00 am for their jobs. His mother reaches at home at around 8.40 am. But in this 40
minutes period of 8 to 8.40 am, there is no one at home to see over and take care of Deepak. So from few months his father closes him in hall and locks the flat, so for more than half hour he is locked in flat till her mother returns from yoga. But due to this unusual response from family, Dipak’s anger and irritation in behaviour has been increased by Mrs. Bhat and so she called his parents to school for counselling. After the various setting with Dipak’s parents, she suggested them to send Dipak at residential special school, because family is not able to deal with pressure and devote time for his proper caring. But his parent’s are in dilemma, they don’t want to send their child to residential school and are not able to devote time for him. So follow daily routine and lock Dipak in flat at morning.

4.1.3 Lack of Leisure Time

Snehal’s mother shared in interview that they have stopped Snehal from sending in school from few months. Snehal is not interested in school anymore. She feels very superior to other girls in school, so she doesn’t feel comfortable at school. But now for 24 hours, her mother has to watch and take care of her at home. Snehal’s mother shared that she lost her earlier freedom to spend her leisure time freely.

4.2.5 Ignorance and Discrimination in Family

There are various reasons behind ignorance and discrimination of mentally challenged children in family. Family’s Low income, stress at workplace, lack of time to take care, preference to non-mentally children and feeling of embarrassment are few major reasons behind this ignorance and discrimination.

One of the teachers shared a case. There is mentally challenged girl who is wearing same underclothes from many years, which are very old, and she has only two dresses. Her dabba (lunch food) items are routine and there is no change in food items, but she tries and shows to be happy and share that everything is normal. Income in family is not the problem, but her non-mentally challenged sister died after delivering a baby and her mother is taking care of baby. So her mother is already disturbed. Her father is well educated. Now this girl works in hearing impairment tools shop at 5 to 8pm, and earn
around 700 hundred per month. But, she expresses her irritation in school with other girls but not at home.

Another teacher shared a case. A mentally challenged girl very rarely talk in school, her father got married before 25 years, and after marriage he came to know that his wife has some disorder or mental problem and so he says that he was cheated. Her elder sister has mental problem, she need full protection and care at a home, she is in home for full time, so this challenged girl has no one to speak and talk she is always mum at home. She has no space to share, father is already stressed.

4.1.5 Religious Explanations

Mr. Patil, Chhaya’s father reminds his experience in interview. On the occasion of marriage of his close relatives he went to his village town. There he had informal discussion with his few friends on many issues. Suddenly discussion turned towards sin and virtue (Pap and Punya). His one close friend argued that the pains and pleasure of human being depend on his/her deeds in earlier birth. Patil remind that his close friend humorously commented at Mr. Patil, that Patil had girl like Chhaya because of his sins in his earlier birth “Paltil Saheb magchya janmatil papache phal bhogtayet”. Mr. Patil shared that it was very embarrassing comment; however he could not defend it because all others were supporting and enjoying it. This incidence reinforces the people’s belief in doctrine of KARMA which has guided thinking and practice of all hindus for centuries. The theory of karma explains the pain, miseries and impairment of an individual as of retribution of sins committed by her/him in previous life. At spiritual level, pains, miseries and disability represent ‘divine justice’. Those supporting this doctrine are convinced that the fortune and misfortunes of the soul and body in this birth are the result of the behaviours in former lives.
4.1.5 Family and Future of Mentally Challenged Children

Unlike the families with able-bodied members, the presence of mentally challenged children adds a serious dimension of uncertainty to the future. There is an every likelihood that during the life of challenged children the family may get disintegrated or some of the able–bodied may migrate to the greener pastures and restrict their responsibilities to sending their regular expenses. Their parents are always fearful of such crises. Almost parents whom I interviewed very seriously responded on this issue. None of them were aware about the National Trust Act, which is one hope towards the secure future of these children. Most of parents believe that, their siblings have to care them after them.

4.2 Society and Mentally Challenged Child

Here, I discuss how mentally challenged children are discriminated in various opportunities in society as well as family.

4.2.1 Discrimination in Opportunities/Recreation

Rajendra is 16 year old mentally challenged from low income group and scheduled caste family. His IQ is in between 45-50, and he is in mild category of mental retardation. Rajendra’s sister, Nayana who is working in government job has the overall responsibility of home as her father is always sick and not able to work.

Rajendra is willing to learn playing Tabla (the musical instrument). When I asked him how and when he developed interest in playing Tabla. He shared that he likes to watch TV and when in many dance programmes he observed the Tabla players, his interest in Tabla increased. With growing interest he insisted to Nayana to make available opportunity to learn Tabla to him. Nayana took him to two Tabla trainers in their area, but both neglected to teach him Tabla.

7 The parents can nominate to trusts for the property in name of mentally challenged children, which can secure the future caring of these children.
The first *Tabla* trainer who is teaching *Tabla* to students from last 10 years in their area is Brahmin. When Rajendra and Nayana approached him, he rejected their request. He shared his problem that, if the parents of his students come to know that he is teaching to *matimand* (mentally retarded) child, they will not send their children to his *Tabla* class. Even he suggested to Nayana to take Rajendra to some *Dholki* trainer. Generally in society there is unjust notion that upper caste people take interest in playing *Tabla*, whereas people from lower class play *Dholki*.

Having rejected from first trainer, Rajendra and Nayana approached to another *Tabla* trainer who is also Brahmin, he did not directly rejected them but demanded almost double charges compare to other students for Rajendra. Paying this doubled charges (Rs.2000/- per month) was not possible to this family. With this bad experience Rajendra and his sister frustrated and gave up the idea of learning *Tabla*. Nayana further shared that the second trainer was also not willing to teach him, that is why he demanded the double charges. At present Rajendra has gave up the idea of learning *Tabla* and fulfilling his interest by playing *Dhol* (big drum) in brass-brand and in socio-cultural programmes such as Ganapati Mandal (Ganesh Festival) and birth anniversaries of various leaders.

This incidence illustrate how stigma of being mentally retarded causes for exclusion of mentally challenged from the opportunities and freedom non-mentally challenged people have in the mainstream society.

**4.2.2 Humiliation and Abuse in Society**

Mentally challenged children are always the easy victims and soft target for humiliation and abuse in society, one major reason is that in general non-mentally challenged people think that they don’t react cant share the incidences to others. The following incidence illustrate how Hapij, a mentally challenged boy experienced abuse in society.

Hapij is 14 years old mentally challenged boy having IQ in between 40-45. His father is company worker and also he had normal married elder sister. Hapij leaves from home for special school at 10.00 am and returns at 4.00 pm. His mother, Ayeshabi runs a small mess at her home and delivers the dinner to around 12 college students who reside nearby
their home. Whenever she faces severe work-pressure, Hapij also help her for collecting the empty dabbas (Tiffin) at morning from the student’s room and sometime deliver dabbas at evening to them.

Ayeshabi shared in interview that, one day after returning from delivering dabba to Mahesh Yadav a college student, she realised that Hapij was very nervous and unhappy, but he did not shared anything to her. After few days Ayeshabi realised same thing and then she thought that something must be wrong and next day she went to deliver dabba to Mahesh Yadav, even she was doubtful about Yadav’s arrogant behaviour. Ayeshabi diplomatically asked to Yadav that Hapij has already shared everything about trouble given by him so they are going to make police complaints against him. Ayeshabi’s trick worked and Yadav Shared whatever happened and asked sorry for it. Yadav agreed that, he do not like Hapij’s visit to his room and food delivered by him, so whenever Hapij was visiting Yadav’s room he was always scolding him and was warning him to not come again. But Hapij did not take it seriously and never shared with his mother. So, last time Yadav agreed that beyond abusing and scolding he slapped Hapij. After hearing this angry Ayeshabi scolded and abused badly to Yadav and stopped his dinner service.

4.2.3 Discrimination in Opportunities at Public Places and Social Functions

Most of time mentally challenged children are neglected by family to take them at public places such as garden, markers, shopping, cinema theatres, etc. In social and family functions, mostly they attend the marriage ceremonies of close relatives with the family members. The avoidance of these children is linked with the bad experiences the family faced in the past, so generally they avoid to take them out to avoid the incidences of humiliations and embarrassment. In our six cases of the study and cases shared by school teacher it is sharply captured that mentally challenged children’s mobility, access and freedom is closely related with the parent’s level of education and income as well as their IQ and physical condition. Following cases clearly illustrate the avoidance of mentally challenged children at public places.
Meera is an attractive 15 years old girl who is suffering from partial brain damage. According to her mother Meera’s IQ is in between 35-40. She also has a younger brother who is quite normal. In their eagerness to look over Meera, her parents have not neglected their second child. Her father is forth class worker in the city municipal corporation, and mother is domestic worker. Her younger brother is normal and studying in high school. Meera like to go outside in market and just for evening walk, but as everyone (parents) is much engaged in their work, Meera very rarely get opportunity for moving out of home except her school. Most of the time, she watch TV at home. Her mother shared that earlier Meera used to go for walk in garden near their home sometimes. But as she has grown and looks very beautiful so they fear for any harassment by the young boys in garden. Her mother said whenever she leaves for domestic work and no one is at home, she requests her neighbours to look over Meera. As Meera moved into adolescent the concerns of parents became deep as they do even in the case of children who are non-mentally challenged. Her parents have trained her to be independent in matter of self-care, cooking, looking after the house. At her school she learnt babysitting. Parents have hope that one day Meera will get married one to someone who knows her history. They feel that Meera is competent enough to look after her children. They also realise it is not easy to find match for her.

Namdeo, 17 years old son of the street vendor has IQ in between 35-40. He showed his disappointment because he doesn’t get free time as he has to help his parents to clean and rearrange the vegetables for the next to sell. Namdeo in his lifetime not attended any social programme except his special school gatherings, his mother shared that generally they avoid to take him in place of heavy rush of people.

Out of six cases except Snehal, no one did get the opportunity to watch the movie in the theatre. Snehal also only once saw the movie in the theatre with the whole family 5/6 years back. Few of these children very rarely get opportunity and access to market place and shopping. Out our six cases, Chhaya is the only lucky who get rare opportunity to go for market place.
4.2.4 Miss-Beliefs and Evil Practices

As shared by teacher the evil and miss-practices are common in low middle class and uneducated parents. In hope of any improvement in child these parents force to believe in quacks and follow their treatments.

One of the teacher shared that a mentally challenged girl was considered and treated as mental disorder/ill case, and treated in hospital, so due to heavy medical dose she was facing many health problems. She is from low income group and slum area, so neighbours suggested and family did all miss-belief-practices (Dora, Tait, Jatra, Buvabaji and other things) so she became more senseless and panic.

4.2.5 Health and Sexual Issues

Health and Sexual issues of the mentally challenged children are mostly not discussed or ignored by the people working with them. One of the teacher shared that sexual problems of mentally challenged are much complex than abuse and violence in these children.

As non-mentally challenged children, mentally challenged children also express and have feelings of love, affection, physical attraction and emotions, but by and large these issues are ignored by their family and people who work with them. One of the teachers who is also engaged in psychological counselling of mentally challenged children and their parents shared that there is need to give controlled freedom to interact mentally challenged girls and boys with each others. It’s natural feeling to feel to talk with opposite sex person, to sit near, chat, touch hands of each other, but generally boys and girls are kept separate in schools and workshops.

One of the teachers shared that behavioural and sexual problems in adult girls are more severe than boys. In menstrual cycle these girls faces problems of no moods and irritation\(^8\). Adolescent girls generally do not share with their teacher, but share it with each others. She further shared that around 20 percent of mentally challenged adolescent

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\(^8\) Teacher shared, though all females face the problem of stress and no mood in menstrual period, the extent and severity is much more in mentally challenged adolescent girls because they can’t share these changes properly.
girls goes through hysterectomy or surgical removal of uterus. Their parents take this decision to avoid the any unwanted incidence of pregnancy and with adolescent girls who are not able to take care of their personal hygiene properly. But due to hysterectomy these girls face problems of hormonal imbalance in future. One girl (Meera) out of six cases of the study went through hysterectomy, and her parents were not comfortable to share much on this issue.

Following are the two extreme cases with sexual problems/issues of the mentally challenged children shared by their teachers.

1) Engineer mother of a adolescent boy told that, at each Amavasya and Purnima (full moon and half moon) they close him in the room in home at night, then he starts his sexual course/masturbation, with high irritation, tears the cloths then after half an hour he became calm, then his parents ask him “is it over?” then they open the door. Otherwise family fear that he will hold mother or sister because he becomes very violent. Family knows and tracks his behaviour/irritations at periodic times.

2) Lady teachers shared that, one girl is always very sexually irritated, she has tremendous attraction towards males, and her mother told that, everyday her bed is wet. This girl does all types of sex, which she watches on Televisions and movies alone. Her mother, brother and father are trying to control her by medicines.

Male teacher shared that, it is heat (Garmi) in adolescent children’s body which need to get out periodically from their bodies, so they give tips to children from moderate, mild and borderline category children for masturbations and to children from severe and profound category they engage them in hard farm work, digging, gardening, walking without any foot wears, so that after tiring whole day they sleeps immediately after dinner at home.

The lady teacher rightly commented, “How we see this sexual issue is important. Because when they (mentally challenged children) are engaged in schools and

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9Here, the terms ‘full moon and half moon’ do not have any mythological or religious reference; it is mentioned by family only for describing the time period.
workplace, they are quiet. But when they became vacant, then their conflict with their bodies begins. These children can’t control their bodies because they have no options as able-bodied or non-mentally challenged people have.”

I conclude this chapter with major observations that, although mentally challenged children face discrimination in family, however family also faces the problem of humiliation in society. It is the society and public places where these children face abuse and humiliations. It is also important to focus on the health and sexual issues of the mentally challenged children.
Chapter V

Conclusion and Policy Recommendations

In this last chapter I summaries the analysis discussions and build hypotheses based on the study findings and observations. At the end of the chapter, I try to give some concrete suggestions for the better social integration of mentally challenged children.

5.1 COMMON BARRIERS IN THE INCLUSION OF MENTALLY CHALLENGED CHILDREN

Mental retardation specifically and disability in general, however, is a human rights issue and it must be clearly realised by all that the disabled including mentally challenged people. Mentally challenged children are an integral part of society and every effort must be made to involve them with the whole society. Children with impairment feel mentally challenged not only because of their mental handicaps and/or physical but because of the barriers society chooses to put up to establish differences between the mentally challenged and non-mentally challenged. These barriers fall in three broad categories:

1. **Environmental Barriers:**
   These are inaccessible barriers to public and private, schools, colleges, offices, transport, information, and communication system. These shut the mentally challenged children out or keep reminding them of their alleged inadequacies and shouting at them that you are not welcome.

2. **Institutional Barriers:**
   These barriers include alienation, exclusion and segregation from key social institutions including education, employment, health, law, recreation, etc. Direct and indirect discrimination against the mentally challenged children prevents them from taking full advantage of these services.

3. **Attitudinal Barriers:**
   The non-mentally challenged children, in general, view and treat the mentally challenged with prejudice and, in varying degrees, regard them as incapable, inadequate, resentful, pathetic, tragic, pitiable, abusive, aggressive, immoral,
unhealthy, dependent on charity, costly for society to support, drain on family resources, inferior, unemployable, etc.

These barriers, as well as many others, are the result of prejudice born out of ignorance and misconceptions due to wrong information and value-system. It is essential that steps be taken to remove such barriers and eradicate widespread discrimination against mentally challenged children. These children must also be offered wider and just opportunities to live independently in society with dignity and freedom to contribute to the richness of society in accordance with their skills and talents.

5.2 Hypotheses Formulation

As the study is exploratory in nature, with the data findings and observation made in the study, it develops few hypotheses which may be tested and quantified in further studies. Rather than hypotheses testing and generalization of findings of the study, the in-depth analysis of research concerns by applying multi-stakeholder and multi-method approach in study help to formulate following hypotheses.

1. Compare to non-mentally challenged children, mentally challenged children also have their own interests, hobbies, and aspirations about future.
2. Family’s unwillingness, pressure, and biased perception about non-mentally challenged children prevent and influence the friendship patterns between non-mentally and mentally challenged children.
3. The misconceptions, lack of right information, and the value-system of mentally challenged children help to determine their perceptions about mentally challenged children.
4. Access and opportunities to mentally challenged children at public places is determined by parent’s education, income, work and family stress, and their experiences of humiliation and discrimination in society.
5. Mentally challenged children face more humiliation and discrimination in common opportunities and services compare to non-mentally challenged children.
6. Sexual issues and problems of mentally challenged children which they face are more serious and severe than issue of access to public places and opportunities in society to these children.

As the formulation of hypotheses is the major output of pure inductive qualitative studies, I arrived at above hypotheses after the analysis in the study. However, these may be tested and quantified in further studies.

5.3 Towards the Solution

There is no dearth of evidences to show that mentally challenged children have been, are, and will remain for a long time, in inferior positions when compared with their mentally non-challenged counterparts. These disadvantages are the result of their social oppression and careful segregation from basic facilities like health, education, employment, finance, recreation, and in mainstream opportunities. However, I believe, the effective and meaningful implementation of normalisation and integration processes through effective tools can increase the possibility of feeling comfort in family and society to mentally challenged children.

5.3.1 Normalization: This concept, which has wider acceptance, has had a powerful influence in the inclusion of excluded groups in society. In context of mentally challenged children, in simple terms, normalization means ensuring that the same environmental conditions of everyday life are available to people with mental retardation as they are for non-mentally challenged children. It also means providing them with facilities to enable development of their full potential. Positive social and neighbouring atmosphere play the crucial role in mitigation and adaptation of these challenged children in mainstream society. How the spaces available in society for development of various skills in children respond to the challenged children determine the confidence building of these children.

5.3.2 Social Integration: Individuals with mental retardation should become an integral part of society; they should not be isolated, segregated or discriminated against in any
fashion. Civil society groups and public private institutions should collectively fight for the dignity of mentally challenged children and implementation of legislative safeguards for their rights and full participation. At the same time it is crucial that entire society should be educated to set aside its discriminating practices as well as wide spread aversion for mentally challenged children and to stop regarding them as economically non-productive members and as the victims of some personal tragedy. But such type of integration does not mean making mentally challenged children ‘normal’ but that being mentally challenged should become irrelevant in their dealing with societies- ranging from mobility, comfortable access to public places, equal treatment as their non-mentally challenged siblings in families, access to recreation, education and training, finding employment, marring and having a family, using public transport, etc. Integration means creating a caring society where mentally challenged and non-mentally challenged share experiences of equality and non-discrimination. Integration means that it is not sufficient to make policies, legislative framework and programmes aimed to creating a barrier-free world but to create positive attitudes, resources and conditions for such a world.

5.4 Recommendations

With my specific observations and data findings in the study and in general overall observations in this field, I propose following recommendations. I propose, for achieving goals of processes of normalizations and integrations towards meaningful integration of mentally challenged children, we must focus on following key issues.

a) Non-mentally challenged children do not have proper sources of proper and scientific information about mentally challenged children, which lead to build biases and misconceptions about them. Therefore, academic world must accept the position that the time has come to formally prepare and teach disability courses (covering the mental retardation) in schools, colleges and universities. These disability courses should not be only targeted towards awards, certificates, diplomas and degrees but also to make the whole society more sensitive, civilised and responsible. It should not be considered adequate to let the disability concerns
be only a fraction of the studies of doctors, psychologists, journalists, political scientists, educationists, and others.

b) Families of mentally challenged children and whole society in general should aware of rights of mentally challenged children. Therefore, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and its Rules 1996 must be translated into all regional languages and disseminated so that its various provisions, benefits, etc. become widely known to all.

c) Nowadays electronic media (particularly the television) is the major source of entertainment, which has the great attraction in people across the age and gender. Coverage in television programmes must be increased which promote positive attitudes towards mentally challenged children. Print media also should provide such space in their content. Along with this, distorted, negative and inaccurate images of persons with disabilities in films, TV serials, radio and television programmes, books and newspapers should be prohibited and positive and appropriate image should be portrayed.

d) Most of schools for mentally challenged children are government funded private schools. In special schools for mentally challenged children, it should be mandatory and carefully followed that teachers, supervisors and other administrative and support staff members have some concrete background in the mentally challenged children’s issues and they also must be sensitive enough about these children.

e) Most of border-line mentally challenged children (from mild and moderate category of mental retardation) are well manageable and under good supervision, they can assist in many type of work and activities. Appropriate training should be provided to mentally challenged children to start and manage their own small businesses. This will help them to be little bit independent and confident in future life.
f) Recent events in India have demonstrated the limitations of single-disability issue pressure-groups and the advantages of inter-disability self-advocacy approach. Such healthy trends must be systematically strengthened. Civil Society groups, various private and public institutions and academicians concerned with mentally challenged children must work hand in hand with their counterparts working on other disabilities,

The most important message of this study is that mentally challenged children must not be regarded as “different” or "aliens". I expect and suggest the policy decisions and the programmes for mentally challenged as well as social mindset should define and classify impairment as ‘lacking part of or all of limb, or having defective limb, organism or mechanism of the body’ and disability as ‘the disadvantage or restriction of activity caused by a contemporary social organization which takes no or low account of people, who have mental or/and physical impairments and thus exclude them from the mainstream of social activities’. This approach reduces the importance usually given to biological pathology. (Although not dismissing the importance of germs, genes and trauma) and locates the causes of mental retardation and their solutions within society. The response to the mental retardation of an individual should be to adapt the social organizations and society because disability is culturally produced. I hope this discussion will further stimulate the discussion on meaningful social integration of mentally challenged children.
(Appendices)
i) Focused Group Discussion Checklist with Mentally Challenged Children

1. What they like-games/movies/actors/actress, what they want to be in life?

2. What is their schedule (write on paper)

3. What are their entertainment choices?

4. What they want to be in life? Aspiration- ambition, hope, dream, aims, plan, desire, wish

5. With whom do you feel comfortable to share and have chat, in family, and surrounding?

6. Do you have normal friends? Do they play with normal children? What are their experiences?

7. Draw the picture of your friend, give the name, and draw the picture of persons who trouble you and give the name

8. Discuss about the persons (Family, neighbouring, society, Schools) whom they dislike and like? Why

9. What type of bad words, symbols others use for you? How do you react to it?

10. Did you get same treatment as your sibling in family? Explain

11. Do you participate in marriages, family programs and other events? Did you dropped, why?
12 Did you witness physical harassment in family and society? Explain

ii) Focused Discussion Checklist With non-mentally Challenged Children

1 Write five lines about mentally challenged children (whatever you think)

2 What you know about MC (Matimand) children? What words, terms they know and use for these children,

3 From where (sources) and how they did came to know about these challenged children?

4 Do you have MC friends, Neighbours, relatives?

5 What are your perceptions and experiences about MC children?

6 Do you like to play and do friendship with them? If not, why?

7 Role play-
iii) Interview Schedule for Teachers of Mentally Challenged Children

1. From how many years you are working with MC children? Educational background

2. Why did you choose this field, any special reason?

Exploitation in family:

3. Verbal violence— type-by whom-why-how – share cases experienced by you

4. Physical violence— type-by whom-why-how- share cases experienced by you

5. What type of problem these people face in their families:
   A. Avoiding them in social functions/ marriage/ receptions
   B. Avoiding them at public places
   C. Keeping them locked in home
   D. Avoidance in public places
   E. Keeping in home alone
   F. Not caring, health and personal hygiene problem
   G. Girl’s vasectomy

6. Please share cases which you came across,

7. Exploitation by society:
   A. Not sharing with them, sexually harassment cases,
   B. Physically harassment, exploitation as labour work by opportunists
   C. What are the other exploitative processes of these children?- Explain -

8. What they think about their future, and family’s reactions

9. What is your suggestion to deal with these children’s problem?
iv) Interview Schedule for Parents of Mentally Challenged Children

1. When and how disability occurred and identified? Is it by birth or after birth?
2. Did all family members accept the disability and children’s behaviour?
3. What you think, which problems family face having such child?
4. Share your experiences on these issues
5. Stigma in society
6. People try to avoid inviting for social programs, with child
7. Economic burden
8. Need of extra person to take care (security, hygiene)
9. Relatives and people avoid arranging marriage with MC children’s Siblings
10. What you planned for your MC children after you (caring in future)?
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