Introduction

Leenamol Mathew “Evolving relationships with persons who have mental retardation: An exploratory study” Thesis. Department of Psychology, University of Calicut, 2006
Chapter 1

Introduction
Introduction

1.1 Story of Faizal

Faizal was a 13-year-old boy with Down syndrome, who needed intermittent support. He was the youngest child to parents, who were daily wageworkers. Of his eleven siblings two others were also with special needs. I first met Faizal on the first day of my visit to Sadhana School for children with mental retardation during the fieldwork, on a rainy day in June. I saw him tied with a cloth to the grill of the window. On the other side of the window, the pre vocational class, to which Faizal belonged, was going on as normal with six children in the class. Faizal was a ‘problem boy’ for others in the class and to the teacher. During my subsequent visits to the school, I realised that severe punishments were common and frequent with Faizal.

Professionals who visited Sadhana School had identified two major deficits in Faizal: poor muscle tone and speech impairment. Thus, the physiotherapist and the speech therapist had set different goals and were trying to achieve them. But Faizal, who did not enjoy these therapies, kicked the physiotherapist while an exercise of stretching the legs was being carried out. On another occasion, Faizal spat on the speech therapist who made him to repeat some words. As usual, punishment was the immediate consequence.

Being one among twelve children, Faizal received little attention from home. He longed more attention and love in the school. Often, his behaviours to gain this

---

1 The names of participants and schools used in the study are anonymous, so as to protect the privacy of the students and schools.
2 Currently there is very live debate regarding the use of the term ‘mental retardation’. At the global level, mental retardation, mental deficiency, mental sub normality, mental handicap, intellectual disability, cognitive disability, learning disability, learning difficulty, general learning disorder and mentally challenged are used to refer to the same condition. Since the term, “Mental Retardation” is well known; it will be used in this research.
attention were interpreted as nuisance in the way to achieve the aims of the class by the teachers. Thus, the attempts of Faizal to gain love and care (required essentially for his growth), were interpreted as 'problem behaviours' that require correction through punishments. I approached Faizal differently. Allowing him to take the lead, I joined him in his activities. In few days, I observed that he enjoyed my company, and started to seek me for his needs.

On one occasion, Faizal threw a duster at a teacher, who had shouted at him for taking the book of another student. I found Faizal tied to the usual window for this reason. Having had a bond between us, Faizal requested to free him. On being free, he hugged me to express his gratitude. The next day while playing one student overturned a table and it fell on me, hurting my knee severely. While other students were passive to my pain, Faizal jumped forward to massage my knee, and then rushing to hit the boy who overturned the table over me. I was observing the changes in emotional responses in Faizal.

However, it was not pleasant for Faizal in the evening. The teacher, who was angered with the throwing of duster, complained to the father of Faizal about the misdeeds. This promptly angered his father leading to severely spank Faizal in front of the teacher and other students. While spanking I heard his father saying: “You have been troubling me too much. I am going to tie down you when you reach home”.

This thesis, through eleven cases of the children like Faizal, is an attempt to understand the life and problems of persons with mental retardation.

The field of mental retardation is usually dominated by the 'how to' questions of applied psychology. For such questions, the researchers usually never come out with a simple and natural answer: through love and care. The behaviour of persons with mental retardation is always attributed to, and interpreted in terms of, their
limitations. This style is common to psychologists as well as general public. As a result, their life becomes dominated and defined by their limitations. This need not be the case. This thesis argues that another pattern of life is possible - a more comfortable, more emotionally pleasant, and more enriching kind of life. The life of persons with mental retardation will change if and only if we change our attitude towards them.

1.2 A subjective history of research

My academic and personal interest in mental retardation can be traced back to my M. Phil days. My dissertation was on the stress of teachers of special education. My occasional interactions with children with mental retardation while studying the teacher stress ultimately triggered feelings of empathy towards the children. From then on I was interested to know more about this marginal section of the society. As a first step, I read more about the concept of 'mental retardation'. But I was disappointed at the over emphasis of conventional methods - measurements, classifications, limitations and future prospects of each level, methods of skill training, modification of negative behaviour patterns, and methods of teaching them - to study the children. However, literature provided me an insight into the feelings and behaviour of the children who were victims of the conventional methods. Therefore, I decided to work more on the emotional side of children with mental retardation for my PhD. The idea was, of course, stimulating and challenging. However, I did not have a clear plan on how to go about with my research work. The field experience at this stage provided me more information on the feelings of children with mental retardation who were most of the time undergoing some deficit-based interventions. Therefore, I looked out for an alternative intervention to increase the happiness of these particular children.
The first stage of the study was therefore an exploration to find out an alternative intervention to increase the happiness of children with mental retardation. During my fieldwork in four schools in the first stage, I observed that majority of the children undergoing deficit services are prone to some or the other problems. I have also observed that most of the time, children with mental retardation did not have good relationship/friendship with the people who provide services to them. Therefore, towards the end of the first phase I could come with a proper research plan to study the possibility of developing intimate relationship with children with mental retardation. The experiences in the field taught me the way I should go ahead in my research. The setting and the sample in the study were in fact emerged during the fieldwork. Developing a close relationship with each of the children was in fact a challenging choice for me. However, I was confident about my style of interaction. I defined it in this way – loving, caring, unconditional to the maximum extent possible, not at all trying to change anything, understanding, pleasantly involving in their activities, appreciating their actions, non evaluative, playing, singing, dancing freely talking, doing what they like, and moving where they lead. Thus, the present research was an enriching pleasant experience for me. My notion of people with mental retardation has changed drastically as an end product of my fieldwork. This thesis is a summary of psychological insights gained from such experiences.

This research poses several challenges to the existing conventional research methodology. It doesn't follow the steps dictated by textbooks. It doesn't follow the methodology that is common and suggested by the literature on mental retardation. It doesn't accept the 'objectivity' doctrine. It is neither a 'hypothesis - testing' research nor a 'hypothesis – generating' research. It starts with a problem, and ends with an improved understanding of the problem. During the process of research, the existing
theory has become more concrete, more illuminating and more clarifying. An alternative kind of knowledge is the result of this kind of research.

The fundamental reinforcement for this study is the responsiveness of the participants - eleven children with mental retardation. To clarify the point, let me narrate one specific instance. The dominant behaviours of one participant – Radhika - were unhappiness and loneliness. Relationship building with Radhika was significantly difficult. However, when I expressed concern and empathy in our interactions, she responded to me with the same intensity. We could establish an attachment relationship. When I visited her after one year of the completion of data collection, I could observe that she could sustain the behavioural changes she expressed during the study. She could recognise me and I could recognise that her styles of functioning had undergone basic changes. This illustrates the nature of reinforcements I received from my work. This thesis is devoted to the participants who became my friends and taught me some of the important aspects of mental retardation.

1.3 Research problem

The intervention models for children with mental retardation are deficit focussed because these interventions aim at developing those skills that are absent or low in them. Professionals approach the child with specific goals to achieve with specific therapies, which are efficient in themselves. The focus on the deficit skills has many unintended consequences for the natural growth of the personality of the child. Most important of these consequences is that the social and emotional needs of the child with mental retardation are not met, since the therapies designed in deficit-intervention model focus only on skill development. The literature review on intervention models for mentally retarded children showed that there are no
systematic methods or attempts to understand or to focus on the emotional and relationship needs of the children with mental retardation. Meeting the emotional needs of children with mental retardation is essential to keep them happy, and to help them to grow in mature relationships\(^3\) with the persons they deal with. Hence, the present study attempts to focus on the emotional and social aspects of the life of persons with mental retardation.

1.4 Objectives of the study

The overall aim of the study is to generate psychological insights regarding mental retardation through developing an intimate relationship with children with mental retardation. However, it was disaggregated to three sub-objectives.

i) To study the possibilities of developing an intimate relationship with persons who have mental retardation. (ii) To understand the life pattern and relationship pattern of persons with mental retardation. (iii) To identify the emotional and social issues of persons with mental retardation.

1.5 Methodology

The study, with an exploratory design, adopted qualitative methodology. The study has two distinctive stages. In the first stage four different schools for children with mental retardation were visited. In the second stage, one school was narrowed down and 11 participants were selected. The researcher had attempted to build an intimate relationship with each of the participants. The interaction continued for one academic year. Further, the significant people related with them were interviewed. Based on all these, individual level analyses were prepared. Also, some broad

\(^3\) In one of the relationship skills models, there is a distinction of instrumental skills and relationship skills especially for the children with Asperger syndrome, autism and pervasive developmental disorder (Gutstein and Sheely, 2002). However, in such a model, the relationship is taught like deficit skills. In this study, I consider relationship skills are already inherent in them.
generalizations regarding the emotional and social life of persons with mental retardation were derived from the experiences.

1.6 Structure of the report

This dissertation report is divided into five chapters. After this introductory chapter, the second chapter provides the theoretical and empirical review on the relationships of people with mental retardation. The third chapter is devoted to the narration of the methods used in this study. Individual-level analyses and the inferences derived from them are presented in the fourth chapter. The final chapter describes the summary of the methods and findings of the study.